

# **EXPERIENCES OF RECOVERY IN MENTAL ILLNESS**

**Paul Bibby**

Doctorate in Clinical Psychology  
University of Edinburgh

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## **Abstract**

### **Introduction**

In recent years the concept of 'recovery' has become increasingly prevalent in both government and health service policy, and in the terminology used by mental health service users. The current study examines the experiences of recovery as described by service users living in a rural / semi-rural population. This is in contrast to the majority of similar studies, which have tended to focus on urban centres where population characteristics, and the services available to service users, differ in many ways. As such, the aim of the current study was to add to the growing theory regarding what constitutes recovery from the viewpoint of service users living in a relatively remote area of the UK.

### **Methodology**

Eight adult participants, all of whom defined themselves as either recovering or having recovered from significant mental health problems, were interviewed about their experiences using a semi-structured interview. Interviews were audio-recorded, transcribed and analysed for emerging themes using a social constructionist version of Grounded Theory.

### **Data Analysis & Discussion**

Analysis revealed a consistent set of themes emerging from the participant interviews. These are encapsulated in the concept of reflection and integration, and the dynamic nature of these phenomena over time. Participants made reference to the nature of their problems and the impact they had on relationships, the treatment they had sought and received, and the effects of their experiences on their notions of themselves as individuals.

## **Conclusions**

The findings of the current study are discussed in the light of existing relevant literature and in relation to current policy initiatives. Comparisons to the emerging theory regarding recovery are drawn, and distinctions made between the existing theory and the findings which appear to be particularly pertinent to the sample population. Suggestions for clinical applications are made. Limitations of the study are also addressed, and areas for potential further research are outlined.

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## **1 Introduction**

This introductory section begins by describing various recent policy initiatives that have introduced the concept of recovery into mental health service design and operation. This is followed by a review of relevant literature related to recovery. The various features of recovery are described, and the history of the shift towards recovery-based approaches is laid out. Predominant models of recovery are illustrated and the various means of conducting research into recovery are explored in order to place the current research into context. Finally, the research questions for this study are outlined.

### **1.1 Terminology used in this work**

Historically various terms, such as 'patients' 'consumers', and 'users', have been used to refer to people who make use of mental health services. There has been some debate regarding the appropriateness of the terms used and the degree to which terminology reflects the particular viewpoint or ideology of an author (e.g. Bassman 1997; Nelson, Wiltshire, Hall, Peirson & Walsh-Bowers 1995).

Frequently in older literature, and particularly in governmental policy documents, the term 'patient' was used. This may have been because these documents related to general health service issues rather than mental health issues specifically. This use of terminology did, however, underline the prevalence of a medical model in the general perception of health issues, whether they were related to physical or mental health. This has gradually changed, and a variety of terms have been adopted in more recent years.

In keeping with the current zeitgeist in mental health research and policy documents, and consistent with much of the literature presented here, in the current document the terms 'service user' or 'client' will be used to refer to people who make use of mental health services. Where a particular author has employed different terms, the original terminology will be retained so as not to alter the author's meaning or intent.

Throughout this report reference is made to staff working within mental health services. Unless referred to in a specific role, no differentiation is made between the various professions involved in providing a service (e.g. Nurses, Occupational Therapists, Social Workers, Psychologists and Psychiatrists) and the term 'mental health professional' is used to refer to mental health service staff in general.

## **1.2 Context for the current study**

The direction taken, and the approaches adopted by, mental health services are influenced by a number of factors. Government policy and legislation, research into 'good practice' by advocacy organisations and professional bodies, and advances in the understanding of the factors that contribute to mental health problems have had a profound influence. In addition, the constantly changing social and cultural environments interact with these factors to shape how services are delivered and who are considered important stakeholders. This section aims to describe some of the most significant of these over recent years, particularly in the light of the shift towards involving service users and the emergence of the concept of recovery as a consistent theme.



Mental health services have evolved considerably since the days of Victorian asylums and the formative years of the NHS. With the inception of a National Health Service in 1948 the well-being of the public has been the responsibility of government and as such, government policy and legislation have had significant impacts on how healthcare has been delivered. In Scotland, recent service development and redesign initiatives have been informed by a series of Scottish Executive policy documents that have emerged over the past ten years. Principal amongst these is the “Framework for Mental Health Services in Scotland” document (Scottish Executive, 1997), launched by the Minister for Health and the Arts in September 1997. This document sets out the results of a national consultation carried out over a six month period between October 1996 and February 1997. The findings were drawn from local ‘best practice’, and were intended to provide a template which existing initiatives could use to provide comprehensive services. Detailed guidance and examples of how to develop and implement an effective local strategy to achieve ‘needs led’ services, based on review, audit & research, are outlined. ‘Essential features’ of local mental health services include joint planning & working, multi-agency agreement on local needs and a clear service framework. The document was informed in part by the findings of a Scottish Needs Assessment Programme (SNAP) report entitled “The Involvement of Service Users in Assessing the Need for, Commissioning and Monitoring Mental Health Services” (White, 1997). Intended to cover people with severe and/or enduring mental health problems and dementia, the Framework document is aimed not only at staff but service users and their carers. Significantly the latter are referred to as “partners and stakeholders” (Scottish Executive, 1997, p1) and the document clearly states that they should be involved in service planning and quality monitoring. This early reference to the active involvement of service users

in all aspects of mental health service design and delivery set the tone for future policy developments, service initiatives and research. In particular, the Framework document calls for a review of mental health services to be carried out and asserts that this review should “obtain feedback from people who receive services and their carers to establish what works well and what does not” (ibid, p10).

In February 2003 the Scottish Executive went on to publish “Partnerships for Care – Scotland’s Health White Paper” (Scottish Executive, 2003 (a)). This document focuses in particular on health promotion, with patients and standards being seen as key drivers of change, and frontline staff as being crucial to the success of processes of change. In his Ministerial Foreword, Malcolm Chisholm (then Minister for Health and Community Care) spoke of a “culture of care developed and fostered by a new partnership between patients, staff and government” (ibid, p5) and emphasised the need to place patients at the centre of new services. The document goes on to advocate treating patients with dignity and respect, encouraging them to provide feedback (which is subsequently listened to) and be involved in decision-making. Partnerships for Care also looks more widely than the Health Service alone, and recognises that health is affected by broader issues within society. Although not solely aimed at mental health issues, reference is made to mental health in several contexts. Mental health issues are cited as a national priority area (ibid, p. 45). Reference is made to mental health alongside physical health, in particular the rising suicide rates in young males and self-harm in young people. Comment is also made on the need to remove the stigma attached to mental illness and improve the public’s understanding of mental well-being (ibid, p 36).

A whole chapter of the White Paper is devoted to 'Listening to Patients'. This acknowledges that society has changed since the NHS was formed and people's expectations have changed along with it. The document reflects that people now expect to be involved in their own care and treated as individuals and states that "meeting people's changing expectations while encouraging greater personal responsibility is a key theme of the White Paper" (ibid, p17). It introduces the concept of this being key to a more effective and high quality healthcare system, and talks of a "culture of patient focus" (ibid, p18). This comprises participation (seeking people's views, and subsequently treating them as equal to clinical and financial performance standards, and acting upon them), empowerment and partnership, especially regarding decisions about care and treatment. The document emphasises that clinicians "must involve patients and be responsive to patients – for some, a culture change from the past." (ibid, p62). The White Paper also echoes the earlier Framework document in emphasising that this inclusive approach extends beyond service users to carers and families. The document also advocates ongoing training and professional development in the area of communicating with patients

'Partnerships for Care' provides little direct guidance about how improvements are to be achieved, although does give some examples of good practice. "Improving Health In Scotland: The Challenge" (Scottish Executive 2003 (b)) sets out four major themes intended to focus activity: early years; the teenage transition; the workplace; and supporting and developing healthy communities. Mental health is included in the overall target of improving Scotland's health generally, and 'Mental Health and Well Being' is one of the Special Focus Programmes outlined in the document (ibid, p34-35). As well as encompassing the improvement of

mental health within the core activities of all four of the major themes, three further actions designed to achieve improvements in this area in particular are outlined. These are the implementation and support of the “Choose Life” suicide prevention initiative, the development and implementation of the “See me....” anti-stigma campaign (both launched in 2002) and the establishment of a three-year National Programme Action Plan.

The National Programme was launched in 2001, with the National Advisory Group being established in 2002. Local authorities, voluntary agencies, community groups and people who have experienced mental health problems and their carers were consulted, and the National Programme for Improving Mental Health and Well-Being Action Plan 2003-2006 was subsequently published (Scottish Executive, 2003 (c)). This had the overall aims of achieving greater social justice by addressing mental health inequalities, and reducing the ‘opportunity gap’ experienced by people with mental health problems. Key themes in the Action Plan include the active promotion of positive aspects of mental health (as opposed to traditional focus on deficits, problems and mental ill health) and increasing awareness of a whole lifecycle view. This considers the importance of the early years, but also of working life and later life – in mental health practice. Better mental health awareness is promoted through a “promotion, prevention and care” approach (ibid, p8), and the importance of psycho-social factors such as social support networks, housing and employment are recognised. These are identified as areas where improvements need to be made, proposing that good mental health is not just a health service issue and emphasising that community life is important and needs to be facilitated for those with mental health problems.

Within the Action Plan, specific aims were stated in terms of raising awareness and promoting mental health & well-being, eliminating stigma and discrimination, preventing suicide, and promoting and supporting recovery. The aims related to eliminating stigma and discrimination and preventing suicide drove the initial focus of activity between 2001 and 2003, leading to the inception of the “See me....” and “Choose Life” campaigns, and the launch of the “Breathing Space” telephone and web-based support service for people (particularly young men) experiencing low mood or depression. As well as recognising the impact of wider psycho-social elements on mental health and recovery from mental illness, the aim related to recovery led to the formation of the Scottish Recovery Network (SRN). The SRN was tasked with improving the understanding of what helps recovery, and has subsequently undertaken a major piece of narrative research to investigate this phenomenon from service users’ perspectives. The SRN is also responsible for disseminating information about relevant research and evidence related to recovery. The SRN has since become a significant force in promoting and supporting recovery approaches throughout Scotland, utilising evidence gathered both locally and drawn from initiatives around the world. The SRN’s work will be considered in more detail later in this document.

Alongside the various policy documents referred to here, there has also been fresh mental health legislation introduced in Scotland in recent years. The Mental Health (Care and Treatment) (Scotland) Act 2003 (Scottish Executive, 2003 (d)) differs from previous legislation in that it contains guiding principles related to how the Act should be interpreted and used. These principles were based on the Millan Principles, developed following a review of the Mental Health (Scotland) Act 1984 (Scottish Executive,

2001) which included significant representation from service users and carers. Whilst the Act does not make specific reference to recovery-based approaches, the principles contained within the Act do reflect the values inherent in a recovery approach, and also reflect various Millan principles such as reciprocity, participation and respect for carers. As such, the Act provides a legal framework upon which recovery-based approaches can be delivered.

More recent policy documents emerging from the Scottish Government include “Delivering for Mental Health” (Scottish Executive, 2006) and “Better Health, Better Care: Action Plan” (Scottish Government, 2007 (b)). “Delivering for Mental Health” is the Scottish national mental health delivery plan and aims to accelerate improvements in mental health services. The document advocates greater service user involvement, and the tailoring treatments to the needs of individuals. It adopts a holistic approach, in several ways. At a personal level, reference is made to the link between physical and mental health, health promotion, and equitable access to it. Once again there is a focus on the promotion of good mental health, alongside physical health and wellbeing. At a more systemic level, the NHS, local authorities, the voluntary sector and statutory agencies, as well as clients and their carers working in partnership are all seen as being part of the solution to mental health difficulties and the impact that they have on clients’ lives. In his Ministerial Foreword, Lewis MacDonald MSP (Deputy Minister for Health & Community Care) states that “service users are central to their own care, treatment and recovery. Patients and carers should therefore be partners in designing and delivering services.” (Scottish Executive, 2006, p iii). Acknowledgement is also given to the role of social inclusion and social justice in reducing inequalities in mental health, reducing stigma and treating clients and their carers with respect &

dignity, and the importance of supports such as exercise, diet, physical health & relationships is once again highlighted.

Within the document, three Health, Efficiency, Access and Treatment (HEAT) targets related to mental health are outlined. These are: a reduction in the increase in antidepressant prescribing to zero by 2009/10; reduce suicide rates in Scotland by 20% by 2013; and reduce hospital readmissions within one year (over 7 day admissions) by 10% by the end of 2009. A further target of achieving improvements in early diagnosis and management of dementia was added later in 2007. These targets are supported by 14 Commitments. Rather than provide a prescriptive structured plan, the document sets out a 'functional model' of all key elements that need to be in place.

In the context of the current study, Chapter 1 of 'Delivering for Mental Health', concerned with improving patient and carer experience of mental health services, is most significant. The document discusses changing cultures and behaviours in health services to improve the experience of all who work in it or have contact with it. Commitment 1 relates to the development of "a tool to assess the degree to which organizations and programmes meet our expectations in respect of equality, social inclusion, recovery and rights. The tool will be piloted in 2007 and be in general use by 2010." (ibid, p1). Work to develop the tool is currently being led by the Scottish Recovery Network, and will allow assessment of services in terms of equality, social inclusion, recovery and rights. It is also designed to identify where change is needed.

Other significant elements of 'Delivering for Mental Health' include the introduction of the concept of peer support workers, defined as "trained

staff who themselves have direct experience of mental illness who are part of the care team.” (ibid, p2) The document outlines plans to develop a training programme for peer support workers by 2008, with workers employed in 3 broad areas later in 2008 (this forms the basis of Commitment 2).

‘Delivering for Mental Health’ also seeks to improve the way that long-term mental health conditions are managed, suggesting that the use of Integrated Care Pathways (ICPs) for illnesses such as schizophrenia, bipolar disorder, depression, dementia and personality disorder would serve to set clear expectations of what service users can expect. As with previous policy documents, the document seeks to guide professionals to think in a wider sense than the immediate illness, and states that “a good ICP will look beyond treating the disorder and will focus on the full range of needs and capabilities of the individual” (p 6). Employment issues for those with mental health difficulties are also highlighted as an area where further work is needed to improve the experience of service users.

Operationally, the adoption of recovery approaches in Scottish mental health services have been further championed by the publication of the Mental Health Nursing Review (Scottish Executive, 2006 (b)). This review directly recommends using a recovery approach and advocates supporting the ongoing development of this via a national training framework. The review also emphasises the need to involve service users and their carers in the selection of nurses entering training, and in service development initiatives.

‘Better Health, Better Care: Action Plan’ was published by the Scottish Government in December 2007 and was informed by responses to the



earlier consultation prompted by publication of 'Better Health, Better Care: A Discussion Document' (Scottish Government, 2007 (a)). The broad remit of the initiative was to "help people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care" (Scottish Government, 2007 (a), p2). Although aimed at the healthcare system in Scotland generally, the document states that mental health continues to be one of the national clinical priorities.

In terms of mental health specifically, the Action Plan again makes a commitment to review the approach adopted in Scotland to improving mental well-being. Reference is also made to the link between deprivation and mental health problems, both in terms of causation and consequences. The report highlights the impact that deprivation has on deaths of males under 65 from suicide, and deaths in this age group "linked to mental and behavioural disorders due to the use of drugs and alcohol" (Scottish Government, 2007 (b)), where significant increases are reported over the past 20 years.

The Action Plan asserts that, despite good progress over recent years, there is still work to do in the areas of mental health improvement, prevention of mental health problems and improving many aspects of the lives of those with mental health difficulties, including recovery. Stigma and discrimination are again highlighted as areas that continue to require addressing, as are mental health services for children and young people. Key workers at all levels and in all sectors are encouraged to be more literate regarding mental wellbeing. It is emphasised that "mental health and wellbeing literacy should also include a recovery-oriented approach, so that people with a mental illness are enabled to lead and direct their own wellbeing and recovery." (ibid, p21).

‘Towards A Mentally Flourishing Scotland: The Future Of Mental Health Improvement In Scotland 2008-2011’ is a partner document to the ‘Better Health, Better Care: Action Plan’ and was produced to direct NHS boards, local authorities and other key players in supporting planned improvements in mental health from 2008 to 2011. The document also sought feedback on what may be required to achieve the goals set out in the National Programme. It was published by the Scottish Government in October 2007 and set mental wellbeing as a significant element not only within a health framework, but also within a wider social, economic and cultural context. It centres on facilitating change within individuals, based around a dual continuum model that encompasses both mental wellbeing and mental illness. Mental wellbeing is described as ranging from ‘languishing’ (a state of poor mental health) to ‘flourishing’ (good or high mental health status). Similarly, mental illness ranges from minimal to maximal levels, with daily functioning being increasingly affected as severity increases. By combining these two continua, a person can be placed within one of four quadrants depending on their level of both illness and wellbeing, and can have a mental illness diagnosis but still experience a high level of wellbeing. The paper describes a need to “enhance people’s mental health and wellbeing, so that they are able to flourish” whilst recognising the need to “reduce the occurrence of mental health problems and mental illness and improve the quality of life of people living with on-going mental health problems or illness.” (Scottish Government, 2007 (c), p4). The requirement to encourage people to flourish applies to people in all four quadrants of the dual continua model proposed in the paper, as well as across the age, race and economic spectra in Scotland.

Proposed themes for future work are based around promotion of mental wellbeing, prevention of mental health problems, mental illness and suicide, and support for those experiencing difficulties. Suggestions for specific actions relating to these themes are made – in the area of support, these relate to reducing stigma, prejudice and discrimination and increasing opportunities in relation to employment, housing and education, as well as social and recreational activities. Significantly, recovery is placed at the heart of these processes and the paper states that “recovery in the presence or absence of the symptoms of mental illness is possible and will be individual to each person and their circumstances. Belief in recovery is key to tackling stigma and discrimination and improving people’s quality of life, inclusion and opportunities.” (ibid, p9). Furthermore, it reports that “Valuing people’s lived experience of living with mental illness is a key part of this agenda.” (ibid, p10).

Aside from policy and legislation, there have been other influential documents that have shaped mental health service design, and the culture that underpins their operation, in recent years. Professional bodies continue to report on advances in the developing understanding of mental illness, not just in terms of causative factors but also in relation to the optimum factors in treatment approaches. The British Psychological Society’s ‘Recent advances in understanding mental illness and psychotic experiences’ (BPS, 2000) suggest a continuum concept, covering the full gamut of mental states ranging from ‘health’ through to ‘illness’ that “shade into each other and are not separate categories” (BPS, 2000, p4). They assert that, as such, diagnosis is not only difficult and prone to error, but also unhelpful to clients and those that support them. The document also attempts to redress the predominantly medical or clinical bias in terms of outcome measures by drawing attention to other measures of

wellbeing, such as social, occupational and relationship variables, which can be used to indicate recovery. Optimism and the maintenance of hope are also seen as central features of the process of living with and recovering from mental illness, but readers are also reminded of the risks associated with stigma and social exclusion that people with mental health problems often experience. Attention is drawn to the growth of the service user movement and with it the increasing acceptance of paradigms other than the medical model to explain psychiatric phenomena. Consequently, the document advocates the development of holistic, trusting, collaborative and individualised services which respect individuals' understanding of their problems, see service users as experts on their own experiences and provide support for clients to regain control of their lives.

From a different perspective, the Sainsbury Centre for Mental Health report 'Keys to Engagement' (Sainsbury Centre, 1998) describes ways in which people with severe mental illness and who have traditionally not engaged well with formal services can be better served. The document points out the considerable risk that non-engagement can create, particularly in terms of social exclusion and the negative impact that this has on mental health status. As well as describing the type of services that may be more effective (assertive outreach, supported accommodation, activities and occupation), the ways in which services may be more successful in securing engagement with clients are also laid out. Based on international research and best practice, recommendations for service design are offered with the underlying message that "the style of working by staff is key to engagement - they must be able to go out and meet people on their terms" (Sainsbury Centre, 1998, p9).

## 1.3 Recovery

### 1.3.1 Definitions and features of recovery

As reference to recovery in policy documents has increased, understanding exactly what defines or constitutes recovery has become increasingly important. Harding, Brooks, Ashikaga, Strauss & Breier (1987), reporting the findings of a 32-year follow-up study, found that people with chronic and severe mental health conditions had been able to achieve “considerable improvement or recovery” (p178). The authors went on to point out that these findings corroborated other longitudinal studies from Europe, and suggested that people with severe mental illness are nonetheless able to live relatively healthy, independent lives.

The traditional view of returning to a state before the onset of illness or symptoms has generally been rejected in favour of a subtly different meaning of the word ‘recovery’. Anthony (1993) defines recovery as “a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.” Recovery in this sense is therefore more to do with hope, optimism and the utilisation of strengths (either pre-existing, or that have developed through the experience of mental illness) than with returning to a ‘normal’ state. Lefley (1994) contrasts this with the traditional way in which services are delivered, commenting that, whilst these services strive hard to provide care and management of clients’ conditions, they do so with little hope of achieving any significant improvement in the lives of service users.

Other authors (Deegan, 1988; Mead, 1997, cited in Curtis, 1997) have drawn attention to the individual's part in the recovery process, in terms of shifting from seeing oneself purely in terms of a "sick" person to a view of the self as a human being having many roles, and of (re)establishing an identity for oneself (as opposed to allowing professionals or services to influence this definition). In an early attempt to exemplify what the recovery process is, Sullivan (1994) found that relationships with others, actively seeking out challenges (e.g. in terms of employment) and drawing on their own strengths appeared fundamental to recovery. The ability to make one's own choices, and the process of maturation (involving self-acceptance and taking responsibility for oneself) were also key themes. More recently, Mancini (2005) proposed that self-efficacy, in terms of gaining a more competent self of oneself, is a central aspect of recovery. Pettie & Triolo (1999) propose a developmental model, in which the search for meaning and the construction of a positive identity are central in recovery, and are seen as being closely related.

Jacobson & Greenley (2001) go further than the individual level alone, to assert that external factors also play a part in recovery. Whilst they agree that internal conditions such as hope, healing, empowerment and connection to others are vital, they also lay out a model in which external conditions, such as adherence to human rights, a positive healing culture and services that are oriented towards recovery are critical. Their model therefore goes beyond the individual to encompass the services with which service users (hopefully) engage, and suggest that neither will be truly effective without the other. This kind of interactive model, with the individual reconnecting with their environment, has also been proposed by Forchuk, Jewell, Tweedell & Steinnagel (2003). They describe a recovery process that begins at the individual level (characterised by

improvements in cognitions and emotions) and which continues through a series of reconnections with external elements such as mental health staff and family. They explain this transition as being suggestive of a shift from initially internally-based thinking to a cognitive style more focused on the wider world. Continuing this thread, Laithwaite & Gumley (2007) also suggest that the development of relationships with staff and family in particular had an influential effect on how people recovering from psychosis began to redefine themselves.

Many authors (Anthony, 1993; Davidson, 2003; Berzins, 2006) also posit that recovery can continue to take place whilst symptoms of mental illness remain. Bradstreet (2004, p7) states that recovery “looks at life first and symptoms second and proposes that the opportunities available to members of a community should not be determined by their mental health. It is about much more than the absence of symptoms”. Deegan (1996) states that “the goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human.” (p92). In this respect, it could be argued that recovery is not that different from what many people, with or without mental health problems, seek to achieve in their daily lives.

In what has been hailed as one of the largest narrative research studies ever undertaken, Brown & Kandirikirira (2007) found that central to most people’s conceptualisations of recovery are factors such as developing a positive view of oneself, having meaningful activities, purpose in life and hope for the future, and having contributions and choices in life validated and valued. The right mix of treatment and support, as well as supportive relationships, were also highly valued by most participants.

Curtis (1997) reported that “while there is a plethora of ideas about what constitutes the recovery process, there is no clear-cut consensus at this point”. This sentiment was echoed two years later by Young & Ensing (1999). More recently Mancini, Hardiman & Lawson (2005) described recovery as “a complex, multidimensional and subjective process of growth, healing and transformation” (ibid, p48) in which the development of a positive sense of self is a critical part. Similarly, Berzins (2006) reported that, despite much discussion and debate in mental health literature, no single definition has yet been achieved. Berzins does, however, point to “a general consensus that it is an individual process of changing personal attitudes, values, goals and skills in order to live a satisfying and hopeful life.” (ibid, p7).

Despite the apparent lack of a definitive, all-encompassing statement about what recovery is, from the literature it is clear that it is a highly individualised, personal and personally unique process for most service users, which may take many years and develop in a very non-linear fashion. Recovery has been described as “a journey, not a destination” (Mental Health Commission, 2001) and this statement seems to eloquently encapsulate the spirit of the recovery movement.

In defining what recovery is or constitutes, it is also important to outline what it is *not*. Deegan (1988) asserts that recovery is not a passive process that is done to individuals, but rather an active process that clients experience for themselves. In the process, she distinguishes recovery from rehabilitation – recovery being seen as the foundation upon which rehabilitation can be based. Crucially, Deegan writes from the perspective of a person who was diagnosed with schizophrenia whilst still at high school, and can therefore relate her experiences directly as opposed to



having elicited them from others. She also provides an insight into an area of recovery that is not always reported, namely the difficulty involved in coming to terms with her diagnosis, denying its existence, and experiencing despair and anguish. Deegan also makes reference to how recovery comes about – not as “a sudden conversion experience”, but as a series of “small triumphs and simple acts of courage” that follow the turning point that is represented by hope (ibid, p14).

At a more institutional level, Bradstreet (2004, p7) states that recovery should not be used in the form of a measuring stick to assess whether or how much people have recovered, nor should it be used as a way of moving individuals through services quickly. There have also been criticisms levelled at the term ‘recovery’, originating from unwanted comparisons to physical health with its implications of having been ill or unwell at some stage (Turner-Crawson & Wallcraft, 2002). There have also been objections from both service users and professionals that some clients may feel ‘recovery’ implies an ability to recover which not all clients may either possess or aspire to, and which consequently excludes or discriminates against these individuals (Schinkel & Dorrer, 2007). Lehman (2000) reminds us that what he terms “the ‘recovery’ rhetoric” can be used to position mental health service users as “the oppressed victims of mental health treatment providers and systems, an anti-therapy philosophy that would encourage persons to free themselves of professional treatment” (p329). Lehman goes on to advocate a more egalitarian model of service delivery, where service users are better informed and are more actively involved in their treatment, but where disengagement from treatment is best avoided. In a similar vein, Herbert Peyser (2001) cautions against blindly adopting a recovery-based attitude towards all individuals with mental illnesses on the basis that, due to the nature of the condition, some

individuals at some stage of their illness will be better served by involuntary treatment. He concludes his critique of one version of a recovery model by stating that “there are dangers in going too far with *parens patriae*, but there are dangers in going too far in the other direction” (p487, italics in original article) on the grounds that clients may be left more vulnerable if compulsory treatment is withheld.

### *1.3.2 The global shift to recovery approaches*

Internationally, or at least in westernised, industrialised and English-speaking nations from which information is readily available, a recovery focus has been advocated in mental health policy for almost a decade. It has been suggested that this has developed from the increase in service user involvement, and also from a shift in psychiatric thinking which now seeks to help people overcome or live with the limitations that their mental health problems impose, integrated as far as possible in the community (Mental Health Commission, 2001).

In 1998 New Zealand’s Mental Health Commission produced the Blueprint for Mental Health Services, which instructs services to place recovery-based approaches at the centre of service delivery. Since its inception, this initiative has progressed further and, through the process of various monitoring and evaluation studies, New Zealand has devised a set of competencies through which mental health workers can introduce recovery approaches into the services in which they operate. The Mental Health Commission’s ‘Recovery competencies for New Zealand mental health workers’ (Mental Health Commission, 2001) not only defines what the required competencies are, but also provides resources (in the form of adjunctive reading material) to assist workers in developing and utilising

these competencies. Ten broad areas of competency are defined, including understanding recovery in both a local and international context, recognising the resourcefulness of people with mental health problems, respect for individuals and their rights, and encouraging and facilitating user involvement in their care. Although drawn largely from mental health literature and training standards for mental health workers, the final set of competencies were achieved only after consultation with service users, their families and communities. The impetus to utilise recovery approaches in New Zealand has been further maintained by the publication by the New Zealand government of 'Te Tāhuhu: Improving Mental Health 2005–2015' (New Zealand Ministry of Health, 2005), which details the current mental health strategy and the major challenges that services face. It is accompanied by a sister document, Te Kōkiri: The Mental Health and Addiction Action Plan 2006-2015 (New Zealand Ministry of Health, 2006), which sets out actions that services need to take to make progress towards the challenges set out in Te Tāhuhu. As such, recovery now occupies a central role in mental health services in New Zealand.

Similarly in the USA, both the US Department of Health and Human Service (1999) and the President's New Freedom Commission on Mental Health (2003) have directed states, via federal policy, to adopt a recovery focus. The achievement of this is very much seen as a key indicator of a shift towards a more modern and progressive system of delivering mental health services.

In the UK, recovery-based approaches in services have also developed in response to government policy advocating increased service user involvement and based on good practice from other nations. In England &

Wales, the publication of *Modernising Mental Health Services* (Department of Health, 1988) and the inception of the National Institute for Mental Health in England (NIMHE) were the catalysts for the move towards recovery-based service models. NIMHE subsequently produced a guide to recovery-based good practice aimed at informing mental health service users about the role that they could play in their own recovery (NIMHE, 2004), based upon the discoveries that other recovered or recovering service users had made. The NIMHE Guiding Statement on Recovery further expressed NIMHE's commitment to "the development of recovery oriented services that can be used by people as tools to support their recovery." (Department of Health, 2005). It sets out a series of principles and values that emphasis education, collaboration between services and service users, the promotion of autonomy, and advocates a strengths-based approach to replace the traditional focus on deficits and dysfunction.

In Scotland, the various policy documents referred to in the previous section have helped shape the ways in which services are designed, commissioned and operated. In addition, the Scottish Recovery Network have adopted and built on the idea of recovery competencies that was first developed in New Zealand, and have begun to define a set of recovery-based competencies for use in Scottish mental health services (Schinkel & Dorrer, 2007). These are built on a foundation of respectful relationships with service users, establishment of trust between workers and clients, and a degree of personal disclosure from workers that allows professional boundaries to be overcome and for experiences to be shared. In keeping with the fundamental philosophy of recovery approaches, active involvement of service users, including effective communication between

clients and services, is also seen as crucial to the success of any approach of this kind.

Significantly, Schinkel & Dorrer also allude to the various obstacles that can hamper attempts to deliver recovery-based services. Key amongst these barriers are those that operate at a systems (as opposed to individual) level, such as the prevalence of a deficits focus of assessment and benefits systems, the clash between training and actual practice, and time and resource constraints. At a more individual level, Schinkel & Dorrer make reference to the often long-term, relapse-laden nature of individual recovery, and the potentially de-motivating effect that this can have on staff. With specific reference to the Scottish culture, Schinkel & Dorrer also hypothesise that Scots may be less comfortable with the notion of challenging professionals and standing up for their rights than service users in other societies.

Whatever the national, cultural and political ideology behind each country's view of recovery, one theme that is repeated throughout the various policy documents is that of recovery not being a 'bolt-on' to existing services, or something that is added as an 'after-thought'. Recovery is very much seen as a new way of thinking about and approaching mental health problems. Many documents also point to the need to take a recovery-oriented approach from the start (e.g. as soon as a person comes into contact with services) rather than being delayed and only employed once individuals are starting to become "well" (Bradstreet, 2004; Anthony, 1993). It has also been pointed out that recovery-based approaches fit much better with community-based service models than those based in institutions (Mental Health Commission, 2001), and this may be one of many reasons why this type of approach has gathered

momentum since community-based care has been the model of choice for service providers.

### *1.3.3 Models of Recovery*

Various recovery paradigms have been suggested and reference to several has already been made earlier in this document. Two particular models have informed and shaped recovery-based services in the UK, and these are briefly reviewed here.

The model that was adapted to form the basis of the NIMHE Emerging Best Practices in Mental Health Recovery document (Department of Health, 2004) was originally devised in the USA by the Ohio Department of Mental Health (ODMH). The ODMH model was developed in collaboration with service users and their families, as well as clinicians and mental health board members. The model proposed a Recovery Process Model in which individuals who are recovering move from a state of dependency to interdependency, via varying degrees of awareness of their situation. Interdependence (defined as the relationships we all have with our partners, families, communities and government), rather than independence, is seen the most important ability that people recovering from mental illness can develop. In the Ohio model the recovery process is considered to be influenced by many factors and is therefore non-linear in nature. This model acknowledges the critical role of clinicians, family and community on the recovery of an individual, particularly in the earlier, more 'dependent' phases of recovery. It also recognises the need for service users to reflect on their own behaviour in the process, and where necessary to modify it in order to allow optimal recovery to occur. In this way, the Recovery Process Model (and the best practice information that

has subsequently been generated) is applicable to all the individuals involved with a particular service user.

Onken, Dumont, Ridgway, Dornan, & Ralph (2002) developed a model that set out to investigate the factors that both help and hinder recovery, and to develop a means of measuring health boards' performance in incorporating recovery-based ideas into practice. As with the Ohio model, this model was based on testimony from service users who had experienced the process of recovery. Having researched the various factors involved, Onken et al proposed a model that defines recovery as "a product of dynamic interaction among characteristics of the individual (the self/whole person, hope/sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (hope, choice/empowerment, independence/ interdependence)." (Onken et al, 2002, pvii). This model has subsequently formed the basis for much of the work of the Scottish Recovery Network (Berzins, 2006), as it is seen as offering a practical basis on which to implement recovery-based practices within mental health services.

#### *1.3.4 Research into recovery*

With the growth of interest in recovery's place in national policy and service delivery documents, research into recovery has also increased. Traditional research into service user issues such as service satisfaction employed various methods to elicit client views. Questionnaires, structured, semi-structured and open-ended interviews, both via telephone and face-to-face, and focus groups have all been used (Jenkins &

Jakes, 1991; Torrens & Harris, 1996; Arscott, Bollom, Dawson & King, 1997; Toone, Reid & Storey, 1999; Gopfert & Mahoney, 2000; Jones, Hughes & Ormrod, 2001). However, many of these studies suffered from relatively poor response rates. Furthermore, the findings of these studies have been questioned on the grounds that dissatisfied clients may simply not respond, thus diminishing the data available on negative experiences. In contrast, and perhaps due to the idiosyncratic nature of the recovery process for most individuals, recovery research has favoured qualitative approaches and attempted to distil the essence of what contributes to recovery from the experiences that service users describe.

Fenton (2000) adopted a narrative approach in a small study with four Maori participants. Her findings were related to the importance of identity (in this context, as a Maori citizen), shame (particularly in a discreet cultural group, which prevents discussion about mental illness), and the use of medication. Fenton also alludes to the potential benefits of participation in research of this kind for service users, reporting that it appears to provide “validation of the journeys” of the participants (Fenton, 2000, p3).

In a subsequent larger study, Barnet & Lapsley (2006) interviewed 40 young adults about their experiences of first-episode severe mental illness. They adopted a narrative-style approach to research, in contrast to the more traditional methods of study focused on organisation, delivery and outcomes. Their stated intention was of “gaining an understanding of what it is like to experience ill-health and health services” in order to be able to “provide fresh, user-centred perspectives that can be used to lead to improvements in design and delivery of services”. (ibid, p7). The authors report that much recovery research was, until recently, based on



the experiences of people who were mainly treated as in-patients in large psychiatric institutions, described as “strange, separate and closed off from ordinary life in the community” (ibid, p2). The authors assert that this type of environment became central to how these service users saw themselves, but was not ultimately helpful in their recovery as clients were removed from their everyday lives and “made to embark on careers as psychiatric patients” (ibid, p2). Barnet & Lapsley go on to report that this approach has changed, and that recovery is now considered possible and attainable within communities. Their findings reflect the impact that services have on the experience of mental illness, as well as the importance of families, friends and community. Barnet & Lapsley also discovered the importance of personal factors such as courage, curiosity and determination, and the need for service users to be able to make sense both of their experiences, and of what services were doing for them.

Elsewhere, qualitative methods have been extensively employed in research into recovery in various forms (e.g. Sullivan, 1994; Young & Ensing, 1999; Ridgeway, 2001; Davidson, 2003; Mancini et al, 2005; Mancini, 2007; Laithwaite & Gumley, 2007). Closer to home, the Scottish Recovery Network was commissioned to carry out one of the largest pieces of research to date in the recovery arena. A total of 64 adult service users (i.e. over 18 years of age) from rural, urban and island populations across Scotland were recruited. Participants were selected from individuals who responded to press advertisements in both local and national press, as well as via recruitment through Scottish Recovery Network mail-shots, existing contacts and word of mouth. Inclusion in the study was based on service users defining themselves as recovering or having recovered from long-term mental health problems. In advance of the research interview, participants were asked to complete a background

information and demographic questionnaire, and were also provided with details of the general interview topics that the research interview would be based on. This latter step was designed to reduce participant anxiety, and to allow them some time to reflect on their experiences prior to the interview itself. Interviews were conducted by one of seven interviewers, supervised by the two principal researchers, with a further interviewer acting as observer. A qualitative approach was taken, utilising a narrative methodology whereby participants were interviewed according to an interview topic guide designed to encourage participants to retell their stories of recovery. Interviews were recorded and transcribed, with observer reflections and observations added. Broad themes were then identified by the principal researchers and interviewer pool, before transcripts were coded by both principal researchers and refined by use of inductive thematic analysis.

The resulting publications, *Recovering Mental Health in Scotland* (Brown & Kandirikirira, 2007), *Journeys of Recovery* (Scottish Recovery Network, 2007 (a)) and *Routes to Recovery* (Scottish Recovery Network, 2007 (b)) are the output of this research. Dissemination of the findings continues in a variety of forms, and the SRN website continues to be not only a repository of those stories of recovery already submitted, but a site where service users can continue to submit their experiences.

The authors do acknowledge certain limitations, such as the 'snapshot' nature of participants' accounts, the individual nature of the accounts provided and the restrictions this imposes on the generalisability of the findings. In addition to these self-identified limitations, it is also worth noting that the participant population was predominantly Scottish and of white ethnic origin. This may further compromise the potential to

accurately generalise the findings of the study to a wider population. The use of a 'pool' of interviewers may also raise questions regarding the degree of consistency between interviews, compared to what may have been achieved had only a single researcher conducted all the interviews.

With the growth of interest in service user involvement, and the recovery movement specifically, several authors have highlighted the need to embrace these factors, and the potential value that incorporating them into both research and practice might have. Tait, Birchwood & Trower (2004) state that "additional research to understand the complex effects of the interpersonal relationship between the client and the mental health care professional appears to be of urgent policy importance."

Others have pointed to the measurable clinical outcomes that are associated with the adoption of recovery-based approaches in mental health services. In a review of international best practice undertaken specifically to inform New Zealand's developing mental health strategy, Curtis (1997) reports that effective rehabilitation tends to achieve positive outcomes in a reduction in hospital use across a range of measures (such as reduced re-admissions and shorter hospital stays); improvements in employment and accommodation status; skills development in cognitive, emotional, social and physical domains; improved client satisfaction and perceived quality of life.

However, despite the apparent weight of evidence supporting recovery-based service models, there continues to be a perception amongst service users that the promotion of recovery as a central tenet within mental health services still has some way to go. One participant in the Scottish Recovery Network's 'Journeys of Recovery' narrative research project

reports that “the thing that has hindered me the most on my recovery is mental health services, as they are. Services are geared towards care and containment and to prevent you becoming a danger to the public. It’s not about making you a fully functioning member of society; it’s about making you compliant.” (Scottish Recovery Network, 2007 (a)).

#### **1.4 Background to the current study**

Recovery is, then, a relatively new area of interest for mental health researchers, and research evidence is in its infancy. As the above review indicates, studies have tended to be based either in England, Australia or New Zealand. In addition, the majority (although not all) of the research to date has tended to take place in large urban settings, often in socio-economically deprived areas with ethnically diverse populations, and where mental health services are relatively large and well-established. Although many studies have quite rightly pointed out that the majority of clients are “concentrated in deprived areas, often inner cities” (Sainsbury Centre for Mental Health, 1998), Tait, Birchwood & Trower (2003) draw attention to the problems of this approach and report that the findings of this body of research “may be limited to urban and inner-city settings”. In their report describing the development of recovery competencies specific to Scotland, Schinkel & Dorrer acknowledge that the more remote areas of the country were not included in their direct contact with service users. They posit that individuals from this type of location “are likely to identify additional problems in regard to the care and support they can currently access” and invite future research to investigate the perspectives of service users from different geographical areas (Schinkel & Dorrer, 2007, p9).

A variety of research methods exist for gathering information about the views and opinions of service users exist, with structured questionnaires being one commonly-used way of obtaining information. However, questions have been raised regarding the reliability and validity of such approaches, not least due to concerns regarding the type of questions asked and the motivation for asking them. It has been suggested that validity is likely to be compromised if the measures used only reflect the researcher's or clinician's interests (Campbell, 1997; Clarke, Scott & Krupa, 1993). In this way, questionnaires have the drawback of restricting both the researcher and the participant to the issues that the questionnaire is aimed at, do not allow for a more flexible and dynamic approach to the research process, and may therefore not produce the rich vein of material that alternative approaches would.

Further research in this area, ideally from discreet population samples, is therefore necessary to contribute to developing a broader understanding of this aspect of the experience of mental illness and which will be relevant to settings different from those traditionally cited in the literature. In addition, a research approach that allows participants to express and explore a range of issues, similar to the ones used in research to date, is likely to produce data from which further theories regarding recovery can be developed. .

The current study will therefore seek to begin to redress this balance by gathering and analysing data from a population sample that differs from those already investigated. Data will be drawn from the population of Moray, a Scottish rural / semi-rural population which differs from the Scottish average on a number of population characteristics. The area has comparatively very low levels of ethnic minority groups, unemployment

(especially due to illness or disability) and benefit claimants, overcrowding and hospital admissions when compared to the national average. (NHS Health Scotland, 2004). A qualitative approach, utilising a Grounded Theory methodology, will be adopted in order that rich data is obtained whilst maintaining sufficient methodological rigour to facilitate meaningful analysis.

## **1.5 Research questions**

Research investigating the diverse elements that constitute the recovery process, and the factors that affect this (related to both service users themselves and mental health services) is a relatively new area of investigation. Where research has been undertaken, it has often focussed on a specific aim or purpose (such as mental health nursing in the “Rights, Relationships and Recovery” initiative), and in many cases has been conducted by researchers who are not Psychologists. As such, theories relating to how existing psychological knowledge informs a better understanding of this process are only beginning to be developed.

Given the relative infancy of this topic as an area of research, and that theories are continuing to emerge regarding what the constituent parts of recovery are, this study aims to further contribute to theory development rather than seeking to test out existing theories via a hypothetico-deductive methodology. This study will aim to gather information about mental health service users’ journeys through the process of recovering from mental illness. Service users’ experiences, both negative and positive, will be explored. The study will focus on the attitudes of participants, concepts such as relationships, respect and the

individual meanings that individuals attribute to their experiences, and will seek to investigate areas such as personal growth and development.

## **2 Methodology**

This section begins by setting out the philosophy behind the research methodology chosen for this study, and explains why this methodology was selected. How the methodology was employed, including participant selection and the research process, is then described.

### **2.1 Theoretical Background**

Given that the topic to be investigated is a relatively new one, where little psychological theory exists, a qualitative methodology was adopted. The intention was not to test hypotheses generated before data gathering began, but to begin to generate theoretical ideas that emerged from the collective experiences of people who had recovered, or were in the process of recovering, from significant mental health problems. Whilst it was considered likely that these theoretical ideas or emerging theories may subsequently be suitable for investigation by other, more qualitative methods, hypothesis testing in this way was not the aim of the current study. In order to provide a formal structure to the data gathering and analysis process, a Grounded Theory approach was adopted.

Grounded Theory has been chosen as a research methodology by a number of recent studies into issues related to mental health (e.g. McCann and Clark, 2003; Gavois, Paulsson and Fridlund, 2006; Laithwaite and Gumley, 2007). Whilst other qualitative methodologies, such as Interpretive Phenomenological Analysis (IPA), were considered for use in the current study, Grounded Theory was selected because of the very 'open' nature of its approach to the research topic. Whilst there are undoubtedly many similarities between Grounded Theory and IPA, the



latter is frequently described as being better suited to understanding *individual* experiences – the “nature or essence of phenomena” (Willig, 2001, p 69) – rather than investigating and offering explanations for experiences that are shared by individuals and which occur in a common context. As the concept of recovery was conceptualized in the current study as a phenomenon that takes place at least partly both within and as a function of an individual’s social context, Grounded Theory was considered a more appropriate methodology to generate broad theories or hypotheses about these experiences that are amenable to later testing or further investigation in this case.

In addition, whereas in other qualitative methods such as content analysis categories of meaning are defined prior to beginning data gathering, Grounded Theory allows such categories to emerge from the data. These categories are not mutually exclusive but rather overlap and interact with each other, and are allowed to evolve throughout the research process. Data that does not fit into the emerging categories is also accounted for, and may indeed become the focus of specific interest in the research. As such, Grounded Theory ultimately generates an inclusive explanatory theory of the topic under investigation, taking a “bottom-up” approach (Brown and Kandirikirira, 2007) which places participants at the core of the research. Participants are therefore able to define and share their own idiosyncratic meaning of their experiences. The resulting theory comes directly from what participants have said, and the interpretations and meanings that they ascribe to their lived experiences, rather than forcing the theory to fit into a pre-determined structure.

Grounded Theory has its roots in sociological research and was first devised by Anselm Strauss and Barney Glaser in the late 1960s (Smith,

Harre & Langenhove, 1995, p29; Willig, 2001, p32) at a time when qualitative methods were gaining increasing acceptance and were becoming more formalised. Glaser and Strauss' intention was to challenge the prevalent idea of the time that research and theory were separate entities and, rather than simply test existing theories by using traditional logico-deductive quantitative methods, to provide a structured and rigorous methodology that would allow new theories to be generated.

Grounded Theory is designed to assist in the generation of new theories that are 'grounded' in the context and data from which they are developed. This is achieved by identifying categories of meaning in the data gathered, and making links between categories, from which theories can subsequently be generated. The Grounded Theory method is considered particularly appropriate to the kind of study where the focus of the research is the individual accounts of recovery provided by participants and the meanings that they derive from their experiences.

Grounded Theory research begins with a broad, descriptive research question which aims to focus the researcher's attention on the phenomena in which they are interested; for example, how individuals with significant mental health problems have experienced the process of recovery. The research question is open-ended and makes no assumptions about what may emerge from the research process. Data is then collected from a variety of potential sources (interviews, focus groups, observations, diaries and other documents) and subjected to a process of qualitative analysis. Analysis is carried out by searching for ideas and categories that emerge from data collected. Data is systematically coded, initially utilising descriptive, 'open' codes to identify ideas from the data. The early descriptive codes are gradually combined, through a process of constant

comparative analysis where information sources are revisited, into more meaningful, higher-level categories. Throughout the process the researcher constantly returns to the data to conduct theoretical sampling – the process of re-sampling data to check the validity of the emerging concepts and theories – and higher levels of abstraction are achieved through theoretical coding, where categories of data are generated by combining lower-level ideas that have some commonality. In this way, the research question itself alters and becomes progressively more focused as the research progresses. This process of continuously moving between data collection and data analysis continues until a "saturation point" is reached (i.e. where no additional major themes emerge from the data). Theories are subsequently generated as a product of the research method – the emerging theory is, in effect, a framework that provides an explanation of the phenomena under investigation. It is an attempt to interpret the phenomena discovered through the research process, and to provide some meaning to what has been discovered. The final output of a Grounded Theory study is not likely to be considered the definitive word on the subject, but instead to be “only a pause in the never-ending process of generating theory” (Glaser and Strauss, cited in Dey, 1999, p117)

Grounded Theory researchers assume no pre-conceived ideas of what themes or categories may be present in the data, and attempt to ensure that they do not unduly influence the research process or the emerging theory. In practice it is acknowledged that researchers are not completely naïve regarding the subject that they are investigating. They are likely to be practitioners in the field being studied, and may have carried out previous research in the area. As such, they are likely to have some pre-existing ideas of their own, and may think of phenomena that emerge in the technical terminology of their profession. This intimacy with the

research topic may unwittingly begin to exert an influence over how emerging ideas are interpreted or described, which may in turn influence how the emerging theory is constructed. Grounded Theory does not pretend that this process does not happen, but instead acknowledges it and seeks to illuminate this process throughout the research. In order to ensure that the researcher's influence on the emerging theory remains transparent, Grounded Theory researchers maintain a 'reflective diary' (usually in the form of memo writing) throughout their interaction with the data. These memos illuminate the researcher's thoughts and ideas as they go through the process of coding, and help to gradually illustrate how ideas, categories and themes in the data are linked together. The reflective diary therefore facilitates researcher reflection on how the themes and categories are arrived at, providing transparency into the development and refinement of the initial research question as the research progresses (Smith, Harre & Langenhove, 1995; Willig, 2001).

Since Glaser and Strauss' original works, several variations of Grounded Theory have emerged. These have been dependent on the researcher's philosophical leanings in terms of how they view qualitative research and the impact that the researcher themselves has on their findings (Charmaz, 1990, 1995; Willig, 2001). In selecting the most appropriate version of Grounded Theory to utilise in the current study, particular attention was given to how participants described their experiences, and how they made sense of these experiences looking back from a perspective of relatively good mental health. The meanings that participants attributed to their experiences were also considered important, as was the potential interaction between the researcher's interests and perspectives and participants' narratives.

As such, the current study employs the social constructionist version of Grounded Theory advocated by Kathy Charmaz (1990). Charmaz defines social constructionist approaches as the “creation of taken-for-granted interactions, emotions, definitions, ideas and knowledge about illness and about self” as well as “researchers’ sociological constructions which they develop, in turn, by studying chronically ill people’s constructions”. Charmaz further maintains that people “experience their constructions as reality” and posits the idea that “ill people’s constructions reflect their understandings of their experiences as well as the diverse situations in which they have them”. She argues for a symbolic interactionist perspective, where “human action depends upon the meanings that people ascribe to their situations” and where “these meanings derive from shared interactions”, tempered by a phenomenological approach – “studying the objects of consciousness”. Charmaz believes that combining these two guiding principles “lead the researcher to look closely at the research participants’ interpretations of their actions and situations” (Charmaz, 1990, p1161).

Charmaz’ approach also formalises the notion of incorporating reflexivity into Grounded Theory research, in the form of memo-writing. Charmaz asserts that “memo-writing gives the researcher a tool for engaging in an extended ongoing dialog with self” and points out that “the dialog with self through memo-making typically helps to separate the researcher from the researched, thereby reducing problems of immersion in the setting or data, ‘going native’, assuming the stance of the practitioner and the like.” (Charmaz, 1990, p1169).

Charmaz’ variation of Grounded Theory has recently been applied to research into the experiences of forensic patients (Laithwaite & Gumley,

2007), further underlining its applicability to and suitability for research into psychological phenomena such as recovery from mental health conditions. They also point out the value of the social constructionist standpoint in formulating “theory generation as the interplay between the researcher and the participant’s system of meaning” and maintain that “the ideas and themes emergent in the method are a product of a process of meaning-making within which the researcher is an active agent.” (Laithwaite & Gumley, 2007, p304). This article in particular also informed the way in which this research report has been laid out. Laithwaite & Gumley provide a clear and concise account of how categories and themes that emerged from their research are interlinked, presented both graphically and in text. The provision a detailed description the most salient categories, preceded by a broad, overarching structure of the findings, illuminates the findings in an accessible way. This report has therefore attempted to replicate their presentation in order to present the findings with optimum clarity.

In keeping with a social-constructionist standpoint, where theory emerges from the data (i.e. individuals’ descriptions – their ‘constructions’ – of their experiences) an open coding paradigm was adopted in the current study. The detailed application of this was guided by Charmaz’ (1990) suggestions for coding. In this way, the codings used are indicated by the data. This hopefully avoids introducing a deductive element by the imposition of coding constraints associated with the pre-determined axial coding strategy espoused by Strauss & Corbin (199), which Melia (1996, p376) refers to as “the technical tail wagging the theoretical dog”.

## **2.2 Participant characteristics**

In order to ensure a degree of consistency between participants, broad inclusion and exclusion criteria were defined for the study.

### *2.2.1 Inclusion criteria*

Participants were mental health service users from within the Moray area, who met the broad inclusion and exclusion criteria that were defined for the study. Potential participants were required to be between the ages of 18 and 65 years of age, in order to be able to give their own consent to take part, and to fall within the remit of Adult Mental Health Services. Rather than select potential participants on ICD-10 or DSM-IV diagnostic grounds (as these often change throughout a client's history), it was decided to identify potential participants on the grounds of the severity of their mental health difficulties. Participants were therefore required to have had a minimum of one inpatient admission to a psychiatric ward at some point in their lives. However, in order to ensure that participants had had a reasonable amount of time to have reflected on their experiences, and to prevent participants who were acutely ill or experiencing residual symptoms from being subjected to further distress, it was stipulated that at least six months had elapsed since their most recent discharge from inpatient psychiatric care. Participants were also required to have at least one ongoing contact arrangement with mental health services (e.g. Day Hospital, Social Work, Occupational Therapy, Psychology etc) in order to ensure that they had adequate support should they become distressed as a result of their participation in the research.

### *2.2.2 Exclusion criteria*

Individuals who were acutely mentally ill and those who were currently psychiatric inpatients (or had been in the previous six months) were excluded. Clients who were known to the researcher (i.e. current or previous clients, or through personal contact) were also excluded on the grounds that such relationships may have introduced bias into the research. Individuals with a learning disability were excluded on the grounds that they did not fall within the remit of Adult Mental Health Services, and may not have been able to give informed consent. Whilst it is acknowledged that such individuals are likely to have a valuable contribution to make regarding recovery, it was considered that their experiences would be better accommodated in separate research aimed specifically at learning disabled service users.

### *2.2.3 Participant selection*

Beyond these inclusion and exclusion criteria, individuals were free to define themselves as “recovering” or “recovered” from an episode of mental illness or chronic mental health problems. They were then free to volunteer to take part in the study by responding to advertisements explaining the purpose and nature of the study.

## **2.3 Safeguards**

In designing the study it was considered possible that, by discussing their experiences of mental illness and recovery, participants may experience strong emotions such as distress, anger etc. It was also envisaged that participants may have questions or concerns about the implications that their involvement would have on their current or future treatment by mental health services. In order to mitigate against these all participants



were provided with information explaining the nature of the study and the requirements of participants, including the potential for distress, via a Participant Information Sheet (see Appendix 1). Potential participants were encouraged to discuss their participation decision with others. They were given a minimum of 24 hours from the time that they received the Participant Information Sheet to decide whether to take part in the research.

It was made clear to participants that taking part in the research would not constitute any treatment or counseling and that, with some exceptions, confidentiality would be maintained in all contact with the researcher. Exceptions to confidentiality, for example if participants were to reveal information that the researcher considered constituted a risk to the participant or others, was explained to participants at the start of each interview (in line with the British Psychological Society's Code of Conduct, Ethical Principles and Guidelines, BPS, 2000). Explicit written consent was obtained before any participation in the research (see Appendix 2, Consent Form). All data was anonymised so that no participant's comments were attributable to them in any way. Interviews with participants were carried out on an individual basis, removing the need to disclose information to anyone other than the researcher. Participants were offered the opportunity to be accompanied by a relative, carer, friend or colleague, on the proviso that the person accompanying the participant did not contribute to or influence the research process.

As participants were, by virtue of the inclusion criteria, already supported by one or more members of mental health services staff, they were encouraged to discuss any issues that the research interview raised with their professional supports. In addition, each participant was informed at

the start of the interview that, in the event that they became distressed, permission would be sought to inform their key worker and/or GP, and that the researcher would ensure that any support that may be required would be organised. Participants were also informed that, should they remain in distress at the end of the interview they would be given additional time to recover. All participants were informed that they were free to withdraw from the study at any stage, with no implications for their ongoing treatment or contact with mental health (or any other) services. Participants were assured that, in such cases, all audio recordings would be erased and questionnaire data related to the individual destroyed. No withdrawal of existing treatment was required in order for service users to participate in the research.

It was also considered possible that the researcher may experience distress as a result of listening to client's experiences of mental illness, or hearing their descriptions of their life experiences. This was managed via the supervision arrangements that exist for all trainee clinical psychologists working in the NHS. The researcher received regular supervision from a Clinical Psychologist, and further support was available in the form of an Academic Supervisor appointed by the University of Edinburgh for the purpose of supervising the research project.

## **2.4 Documentation**

A single-page advertisement was devised to advertise the study in mental health Day Hospitals throughout Moray (see Appendix 3). This outlined the broad aims of the study and provided the researcher's contact details, with the intention that individuals interested in participating in the study could contact the researcher to volunteer. A Participant Information Sheet

(see Appendix 1) provided further details about the study and what would be expected of participants. A Consent Form was designed to ensure that explicit, written consent was obtained from each participant (see Appendix 2).

In response to concerns voiced by Tait, Birchwood & Trower (2003) who reported that the lack of demographic information meant that gaps existed in their knowledge of participant population characteristics, a questionnaire was designed to gather demographic information from each participant (see Appendix 4). No personal identifying information was requested, and the information was solely used to provide information about the participant sample as a group.

In keeping with the Grounded Theory methodology, a semi-structured interview schedule was devised to conduct the initial interviews (see Appendix 5), although it was recognised that the content and focus of subsequent interviews would be likely to change in response to emerging ideas and themes from earlier interviews and subsequent coding. The interview schedule was designed with the aim of eliciting both positive and negative experiences of mental health problems.

## **2.5 Approval process**

Ethical approval for the research was sought from the North of Scotland Regional Ethics Committee (REC reference 07/S0801/123) using the standard application form. Included in the application were examples of all the documents described above. Following the initial application for ethical approval, clarification was sought by the panel regarding participant interviews. Minor modifications regarding retention of data

and minor changes to the Participant Information Sheet and demographic information questionnaire were requested. Once a response had been provided, ethical approval was granted. The project was also registered with the NHS Grampian Research and Development Department, and approval for the project to proceed was subsequently granted. Copies of correspondence with the Ethics Committee and NHS Grampian R&D Department appear in Appendix 6. Within the host service itself, the researcher's Line Manager (Clinical & Counselling Psychology Service Manager (Moray)) obtained the Head of Mental Health Service's support for the project.

## **2.6 Participant recruitment**

Once ethical, R&D and local management approval had been secured, the Lead Clinician (a Consultant Psychiatrist) for the Integrated Mental Health Service in which the research was to be carried out was consulted regarding optimal ways of disseminating information about the project throughout the various Community Mental Health teams. A presentation describing the context, aims and proposed methodological approach was subsequently given to all interested parties at the CMHT 'Journal Club' forum. A variety of additional ways in which information about the project could be shared were identified and meetings with individual Consultant Psychiatrists, Day Hospital managers and staff were held. In addition, the researcher's Line Manager explained the project to the service's Integrated Management Group.

Local agreement to a proposed method of involving clinicians in identifying possible volunteers was obtained. Following a formal request from the Head of Psychology Services, lists of mental health service clients

who met the inclusion criteria, organised by clinician, were created by producing a customised report from the computerised Patient Information Management System. These lists were then distributed amongst the principal clinicians within the Integrated Mental Health Service, together with copies of the advertisement and Participant Information Sheet. Clinicians were asked to inform individuals who they felt would be suitable (that is, their participation would not be likely to cause them undue stress or harm) about the study. It was, however, made clear that the decision to volunteer in the study was to remain entirely with service users themselves and that Individuals would be free to choose whether to participate or not, without penalty. Service users wishing to be involved were invited to contact the researcher directly.

## **2.7 Procedure**

Eight volunteers subsequently came forward. Individuals who volunteered to participate were initially contacted by the researcher to ensure that they a) met the inclusion and exclusion criteria; b) understood the requirements of the study; and c) had the opportunity to ask questions or seek clarification about the study before committing to take part. A mutually convenient time and location at which to interview the participant was then agreed. Participants were identified only by a number assigned to each volunteer, with only the researcher being aware of their actual identity. No participant identifying information was stored once interviews had been completed.

At interview participants were asked to sign the consent form designed for the study, and were given a copy of the Participant Information Sheet and the signed consent form for their retention. Once written consent was

obtained, participants were asked to complete the demographic questionnaire then interviewed about their experiences of mental health difficulties. Interviews were audio recorded and transcribed by the researcher for subsequent analysis.

Interviews initially adopted a broad focus, based on the first version of the semi-structured interview schedule (see Appendix 5) so as to obtain a wide variety of views without prejudicing participants' responses. Two interviews were conducted using this initial schedule and were transcribed by the researcher. Once transcription was completed the audio recordings of each interview was destroyed (typed copies of transcription notes, containing no information that could identify participants, were retained in accordance with the requirements of the North of Scotland Research Ethics Committee). Interview transcriptions were imported into the QSR Nvivo 7.0 software suite to enable analytic codes to be generated and more easily managed. Line-by-line coding was completed on each of the first two interviews. An extract of the interview transcript from Participant 1, together with the initial line-by-line codes that were applied, is provided below to illustrate the coding process.

Transcript	Coding
<p>PPNT 1:</p> <p>We've been discussing this – how you sort of, the whole thing has affected....but I think it's made me a better person.</p> <p>INT:</p> <p>In what ways 'a better person' ?</p> <p>PPNT 1:</p> <p>Because I can put up with more ! We were</p>	<p><i>Becoming a 'better person'</i></p> <p><i>Inner strength</i></p>



from a descriptive style to a more analytical and conceptual level, where a set of categories was generated through a process of constant comparison both within and between interviews and reference to additional memos and field notes. In this way themes were further refined, and views and opinions that were outwith the initial categorisations were identified and used to generate new categories, in order to arrive at an inclusive account of participants' experiences of mental illness contained within a set of high-level categories. Whilst the methodology was guided by Grounded Theory principles, an element of thematic analysis was also employed to generate the broader themes in the analysis.

The process of moving from a descriptive account to a theory of what constitutes recovery was informed by the researcher reflecting on the content of the eight interviews in the light of the existing literature related to recovery and the researcher's broader knowledge of psychological principles and theory. Where this was believed to highlight particularly salient ideas, researcher memos were reviewed and added to as appropriate.

By way of illustration, the memo 'Personal growth' (see Appendix 7) was written once all interviews had been transcribed and the initial coding completed, during the process of searching for consistencies between the narratives that would indicate the emergence of a theory. In essence, the memo records the researcher's reflections on the way in which participants' reflections on their own experiences had not only fostered a sense of acceptance of their situation and gratitude for what they had at present, but had led individuals to see that they had become more self-aware and in some ways better people as a result of their experiences. This created a link between individuals' attitudes towards and their awareness



of their problems, allowing the concepts of 'the self' and the 'nature of problems' to be connected at a theoretical level.

Similarly, the memo 'Benefits from participation ?' was written whilst coding the third interview. The memo arose from the researcher reflecting on the experience of conducting participant interviews, and an awareness of participants spontaneously reporting that they had found the process of telling their story beneficial in some way. This led to a revision of the interview schedule to include a specific question about participants' views on taking part in the research. More significantly, however, it also represents the initial recognition of the idea that the process of reflection on and integration of participants' experiences might be critical in the overall process of recovery. This was to become the over-arching concept in the theoretical model of recovery, and one of the key findings from the research.

This process continued, with themes and categories being refined, until a point was reached where category "sufficiency" was considered to have been achieved. Dey (1999) defines this as "the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications" (p117). The term sufficiency is therefore considered to reflect a more accurate and realistic description of the point at which coding ceased, rather than the completely exhaustive (and in practice virtually unachievable) state implied by the more traditional term "saturation". Given the practical constraints of the current, relatively small and time-limited study, sufficiency was considered a more pragmatic aim whilst still allowing meaningful concepts and ideas to be inferred from the data. Broad themes started to become evident from the first two participant interviews; following initial coding, further interviews and

comparative analysis of transcripts it became clear that interviewees were covering a very similar range of topics which could be developed into distinct, meaningful categories. The decision was therefore taken that theoretical sufficiency had been reached, and participant recruitment was ceased after eight participant interviews had been completed.

### *2.7.1 Development of Themes and Categories*

From the start, participants appeared very willing to talk about their experiences of mental health difficulties and seemed to appreciate the opportunity to take a longitudinal, lifetime view of their problems. Throughout the interviews, participants did not just describe events but made interpretations of them, based on subsequent experiences and learning. They also offered opinions about the personal meaning or significance of their experiences from the vantage point of being able to look back from a position of relative 'wellness'. Within this there was evidence that participants had been able to make some attempt to integrate their experiences into an overall view of their lives up to the present. In addition, some participants spoke about ways in which they were attempting to use this integrated view of themselves to imagine and plan for the future.

After the first two interviews, common ideas began to emerge that were considered worthy of further investigation in subsequent interviews, both to determine if other participants shared these notions and to identify other concepts that participants reported to be important aspects of their experiences. These ideas, and the various elements of them that participants had either spoken about or that were considered to warrant further specific enquiry, were used to generate the revised interview

schedule used in subsequent interviews. For example, participants spoke not only about their subjective experiences of mental illness, but also of the impacts that their difficulties had on a variety of aspects of their lives. The development of this early idea into the later, more substantial category 'Impacts' is illustrated by the contents of the researcher memo written when analysis and initial coding of all eight transcripts had been completed:

### **Memo: Impacts**

*Written Oct 08, following completion of coding and draft concepts hierarchy*

Range of impacts of MI, many of which interact with each other.  
Complex picture ?

Most significant impacts seem to be:

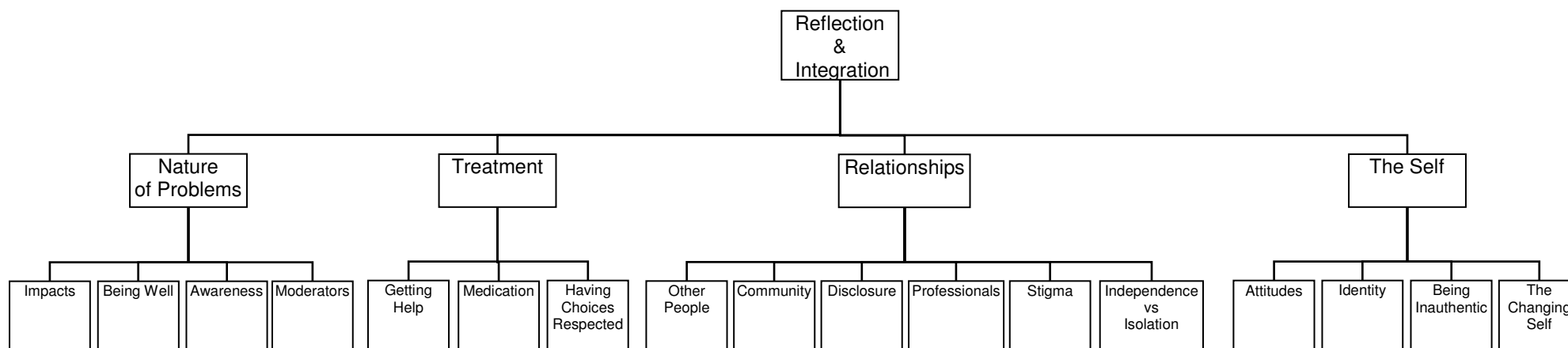
- on families, partners etc - resilience required by partners to stick with it when things get difficult. Raises issue of support for partners, who (participants feel) do not get enough formal support or recognition for the role they provide in supporting patients and maintaining their well-being;
- on self-esteem and general view of self. Much guilt about how others were treated when participants were ill;
- on work (links with 'Work' memo);
- related to losses - of work (and therefore identity etc) but also of friends, relationships, and of hope of recovery.

Relationships to other people, and in particular the ways in which these had changed as a result of mental illness, was another significant topic that most participants made some reference to. In order to clarify how subsequent participants thought about these topics, and to elucidate further details, the revised interview schedule contained specific prompts to ask additional questions. In the broad area of relationships, for example,

prompts were generated to encourage discussion about the roles that other people played (both as individuals and as a community) the importance of other people's attitudes or perceptions, and shifts in participants' ways of behaving towards others. Similarly, in relation to the impacts of mental illness participants were asked about the specific types of impacts that they had experienced, the areas of their lives that had been affected and whether the impacts were considered to have been positive or negative.

As the process of interviewing, coding and comparing transcripts progressed a broad framework began to emerge that appeared to encapsulate the spirit of what participants had been expressing, and the way in which they expressed it. The overarching theme was one of reflection on and integration of past experiences. Within this, participants spoke about their experiences in terms of four broad categories: the nature of their problems, their experiences of treatment, relationships, and their sense of self. These categories, and the sub-categories that are subsumed within them, are depicted hierarchically in Figure 1 (below) and are discussed in greater detail in the following section. A more detailed and dynamic graphical interpretation of how the various categories and sub-categories were conceptualized as being interlinked (as an illustration of the reflective process within the research) is included at Appendix 9.

Figure 1. Organisation of Themes and Categories



## **2.8 Dissemination of Findings**

In addition to the presentation made to the Community Mental Health Teams in the hosting service regarding the aims and proposed format of the research, the CMHT 'Journal Club' was also revisited once all participant interviews and coding had been completed. This provided an opportunity to share the preliminary findings of the research and their potential implications both locally and at a broader, more theoretical level. This forum was also used to discuss the research methodology and potential shortcomings of the study, in order to augment the researcher's own reflective practice.

It is the researcher's intention to make a further presentation of the completed findings and proposed theory generated by the research to the CMHT Journal Club forum.

Participants were informed at interview that the final report of the study would be made available to them on request.

### **3 Data analysis and Discussion**

This study explored the experiences of eight individuals who, by their own definition, were recovering or had recovered from a chronic mental illness. The severity of the various conditions described was such that each participant had at some time in their lives required treatment as a psychiatric inpatient, although at the time the research was conducted every individual was living in the community with some degree of ongoing support from mental health services. The study was prompted by an interest in how mental health service users might experience and describe the concept of recovery, which has been much lauded in mental health research in recent years. The location of the research, in a rural / semi-rural setting within the UK, provided an added dimension to the research and was intended to make some contribution to the dearth of research in such locales cited by previous recovery researchers. In order to add to the developing theoretical models of recovery a Grounded Theory approach was selected, consistent with the predominantly qualitative research methodologies that have generated theories that have begun to emerge to date.

The aims of the research were to investigate mental health service users' perspectives on their own recoveries, from a psychological standpoint, in terms that could be amalgamated into a theory of how recovery works in this population. Notions such as participants' attitudes to their illness, relationships (particularly in a small community) and the ideas of meaning and personal development were the initial sensitising concepts that directed the research.

This section begins by providing a summary of the data gathered via the demographic questionnaire, in terms of participants' age, gender, diagnosis,

previous treatment received, level of education, living arrangements and employment status. Where the analysis reveals information that is considered salient to the overall findings of the research, a brief discussion of these points is offered.

The findings of the eight interviews conducted are then outlined. The findings are initially described in a form that lays out the main issues raised and the relationships between them. The various sub-categories that are contained within the main categories are then described in more detail, illustrated by direct quotations from participant interview transcripts (the page and line number where each quote starts in the relevant transcript have been provided to indicate where in the interview each statement was located). Category and sub-category titles are highlighted in italics for clarity.

The section concludes with a discussion of the way in which the findings can be considered to form a coherent emerging theory of how participants experienced recovery. The theory is discussed in relation to the existing literature on the psychological phenomena that pertain to it.

### **3.1 Demographic data**

Of the eight participants who took part in the study, six were female. Participant ages ranged from 32 years to 62 years, with the mean age of the sample being 49 years. Given this average age, the participants in the current study may not be representative of the entire population of individuals who come into contact with adult mental health services. However, useful inferences from this aspect of the



participant population can be drawn. It may be that it is necessary, or at least more informative, for an individual to have experienced a number of years (or episodes) of living with their condition to be able to reflect on it sufficiently to be able to gain adequate perspective.

The discussion of the interview contents that follows will assert that this reflective ability is a key component in the integration process that characterises eventual recovery. It may therefore be that, whilst recovery is possible either at a relatively young age or following a small number of illness episodes, some individuals may require greater assistance in processing their experiences and integrating them into their view of themselves. This may present an opportunity to deploy 'formulation as intervention' strategies, which are discussed in more detail later in this report.

With regard to diagnosis, all participants had received an 'official' mental health diagnosis or used a term, agreed with their Psychiatrist, to describe their illness. The range of diagnoses cited by participants is shown in Table 1 below.

<b>Diagnosis</b>	<b>Number of participants</b>
Depression / recurring depression	4
Severe depression and co-morbid eating disorder	1
Borderline Personality Disorder	1
Obsessive Compulsive Disorder	1
Long-term psychiatric disorder	1
<b>Total</b>	<b>8</b>

*Table 1 – Diagnoses / terms used to describe participants' illnesses*

Although the demographic questionnaire offered participants the opportunity to record their own view of their diagnosis or an alternative description of their mental health problems, six of the eight participants did not respond. Of the two that did respond, one agreed with the official diagnosis they had received, and one reported that they were 'uncertain' as to how they would describe or classify their difficulties.

As the intended focus of the research was the process of recovery, no inclusion or exclusion criteria related to diagnosis were set (with the exception of service users who were acutely unwell, or classified as having a learning disability).. In addition, constraining participants to specific diagnostic categories would have been likely to reduce the available pool of volunteers, and may therefore have negatively impacted on the quality and validity of the findings. In addition, service users with chronic mental health difficulties may question or disagree with their formal diagnosis, and diagnostic decisions can and do change.

As a result, the range of diagnosed mental illnesses included in the study was not controlled for. It is recognised that participants from a discreet diagnostic sub-set (e.g. those with a psychotic illness) may have different experiences of and reflections on their illness. This may present opportunities for further comparative research in the future.

In terms of the treatment that participants had or were continuing to receive, all eight reported that they had taken medication in the past and were continuing to take some form of medication at present. Similarly, all eight participants reported that they had also received other forms of treatment in the past, and seven of the eight reported that they continued to receive some other form of treatment at present.

Education levels of the participants ranged from no formal qualifications to doctorate level education. The spread of educational attainment across the sample is shown in Table 2 below.

<b>Highest level of education</b>	<b>Number of participants</b>
No formal qualifications	1
O-levels / Standard Grades	1
Further education (SVQ, HNC, HND etc)	1
Undergraduate degree	1
Masters degree	2
Doctorate / PhD	1
Did not respond	1
<b>Total</b>	<b>8</b>

*Table 2 – Educational attainment level of participants*

This analysis shows that the average education level of the participant sample was relatively high, with five of the eight participants having achieved qualifications above those taken at normal secondary school leaving age. It could be argued that those with a higher level of education could be considered more eloquent, and therefore a) be better equipped intellectually to reflect on their experiences; b) more likely to volunteer (due to a degree of confidence in their ability to convey complex ideas); and c) to be better equipped to communicate their feelings and reflections on their experiences. Within the current study there was little opportunity to either control for this, or to determine whether education level had influenced participants' abilities to reflect on and discuss their experience. One participant did state that she felt she had been better treated, and believed that mental health service staff held a greater degree of

optimism for her recovery, because she was seen as a “professional person”. This was, however, an isolated comment and was not corroborated elsewhere in the research. Given the relatively high educational level of the participants, and the potential impact this had on their motivation to volunteer as discussed above, it is possible that the eight individuals who took part in the current study are not representative of the entire population of people accessing mental health services in the study area. As one participant alluded to, the intellectual capacity of participants may have affected the type and quality of treatment they received, based on the assumptions that mental health service staff made about them. It may also have increased participants’ ability to make optimum use of services, for example enabling them to be more assertive or be more actively collaborative in their treatment, which in turn may have positively affected their experience of treatment and ultimately the outcome.

Overall, there did not appear to be a qualitative difference in the accounts of any of the participants. All gave a clear and extensive account of their experiences, and there was evidence in their testimonies that all had reflected a great deal on their illness. Participants’ willingness to contribute to the research may have been indicative of the place in their recovery journey that the contributors were at. This willingness to reflect on their experiences may in itself have implications for the subsequent interview analysis. The opportunity to tell their story may have actually been a part of the recovery process itself. The overall tone of participants’ accounts was generally positive, and all spoke from a position of relative well-being compared to a previous state of mental health.

Although a range of possible living arrangements were offered on the demographic questionnaire, in the event only two of the various options were

endorsed. Three of the participants described their domestic situation as living alone with no formal supports; the remaining five participants lived with a partner or spouse.

In terms of employment status, some participants asked if they could endorse more than one option from the list provided on the questionnaire. It was decided to allow participants to do so, in order to obtain a more accurate picture of the variety of employment situations that participants were in. The range of employment situations is shown in Table 3 below.

<b>Employment status</b>	<b>Number of participants</b>
Not working & claiming benefits	3
Employed full-time	2
Employed part-time and claiming benefits	1
Voluntary, unpaid work & claiming benefits	1
Homemaker	1
<b>Total</b>	<b>8</b>

*Table 3 – Employment status of participants*

### 3.2 Overview of interview findings

A broad over-arching concept, that of *reflection and integration*, was consistently evident in participants' narratives. At the highest level, participants' accounts were characterised by their reflection on and integration of various aspects of their experiences. Participants' descriptions of the process of recovering from mental health problems were broadly categorised into subject areas related to the *nature of the problems* experienced, *relationships*, *treatment* issues and *the self*.

All eight of the participants spoke to some extent about the *nature of the problems* that they had experienced. Within this broad category, participants spoke about the various *impacts* that their mental health difficulties had, their own *awareness* of their illness, the factors that acted as *moderators*, and their experiences of *being well*.

The second broad category to emerge from participants' descriptions of their experiences concerned *treatment*. Within this, participants described their experiences in relation to *getting help*, *medication* and *having choices respected*.

The third broad category to emerge was that of *relationships*, and the ways in which these changed as recovery progressed. Emerging sub-categories were relationships with *other people*, the *community* and *professionals*. Participants also spoke about issues such as *disclosure*, *stigma* and *independence versus isolation*.

The final category related to the self. Within this topic area, participants spoke about their *attitudes*, *identity*, *being inauthentic* and *the changing self* as key components of their recovery.

### 3.3 Interview findings by category

#### 3.3.1 Nature of problems

Initial questions in the interviews were aimed at eliciting information about participants' experiences of their mental health problems. In response, participants spoke about the nature of their difficulties, both in objective terms (such as the onset of their illness, their symptoms and the progression of their condition) and in more subjective terms, in particular in relation to the impact that their illness had on their lives. Most made reference to both the early origins of their problems, and the long-term nature of them. It became evident that these descriptions were the product of a process of reflection, of having taken time to look back over their lives, which emerged as a strong feature of the recovery process. With the benefit of hindsight, participants described how they had been able to see the factors that may have influenced the onset and course of their mental health problems. In this sense, participants spoke of their gradual but increasing *awareness* of the nature of their problems. There were descriptions of an early lack of awareness of the severity of the problems, and of the effect this had:

*P3 – “The first time was not realising how bad it was, and not being able to accept how bad it was, and then it got better as they let me out, and then it got bad but not as bad, and then the third time I went in I thought I shouldn’t have been there – “I’m not stupid, I shouldn’t be in here” - but that’s a stupid attitude, but that’s what went through my mind.” (pg 14, line 680)*

However, participants described how this was replaced by a recognition that problems did exist, and a growing awareness of the age and complexity of their



problems. Many spoke of the varied nature of this awareness and described how it had increased and decreased at different times in their lives. Increased awareness of the nature of their illness was connected to individuals taking a more 'whole life' view of their experiences, and seeing their illness as part of their 'journey' through life. Participants reported that awareness had been brought about by recalling memories of the difficulties they had encountered and gradually learning about their condition, through reading and gathering information and by talking about their problems. As a result, participants spoke of having achieved a form of synthesis of their experiences, of making sense of them and of being able to integrate the various contributory factors and past experiences into a more holistic view of themselves:

*P8 – “I never put things together until I was much older. I mean, it’s only recently that I’ve put my entire life together.” (pg 4, line 196)*

When discussing the nature of the problems that they had experienced, participants also made reference to the *impacts* that had both contributed to and arisen from their mental health difficulties. The former were talked about in terms of relatively small stressors, and of the compounding effect that these could have:

*P7 – “...things start to build up at work as well, because your mind’s just getting more and more occupied with worrying, and me thinking about all my guilt and feeling really bad.” (pg 7, line 340)*

With regard to the impacts of their mental health problems, participants spoke about the impacts on life and the ability to function in general:

*P2 – “Erm...it’s affected my self-esteem, it’s affected my confidence, it’s affected my financial status, there’s been years when I haven’t been able to work. It’s affected a lot of activities I can and can’t do.” (pg 2, line 54)*

Family life, and relationships with partners and spouses in particular, was an area of life that was reported to have generally suffered negative impacts:

*P3 – “I’ve hurt him such a lot – deliberately sometimes. Just a terrible thing to do.” (pg 5, line 247)*

*P8 – “It’s very difficult – I mean, I’ve been with my wife now for 30 years and she knew when I met her that I had problems with depression, and I’d said it might be a bit difficult. But she said ‘Well, we’ll cross that bridge when we come to it’.” (pg 1, line 49)*

Several participants spoke about the lack of acknowledgement within mental health services of the impact that mental health problems have on the partners of service users. There was also a perceived lack of direct support for families and partners, and two participants expressed a view that their health and progress would have been improved had formal support been provided for those living with them and sharing the burden of their illness.

Other impacts cited were those related to feelings of loss, disappointment or regret that many participants had experienced. In this sense participants reflected on their regrets about things that they had done whilst unwell. They also spoke of the losses that they had experienced as a result of their mental health problems, in terms of work (and all that is connected with it), relationships and the loss of hope of some form of recovery. Recognition of these

losses, and attempting to come to terms with them, played a significant role in participants' progress towards recovery.

In terms of factors that participants believed had acted as *moderators* of their illnesses, issues such as early attempts at coping (and their own predictions about how these might work) and having some responsibility for their own problems were raised:

*P4 – “And when I do go on a downer, medication does nothing. I won't take more medication – I just close the curtains, and the door's locked anyway, the phone's out and I just...before probably I used to go and have a drink, and that kinda...that would sort out the depression.” (pg 2, line 64)*

Two participants made reference to the usefulness of a mental health problem in coping with situations. One spoke of OCD as an adaptive way of dealing with stresses that might otherwise have overpowered them, whilst another described making reference to their diagnosis in a light-hearted way to explain odd behaviour.

One particular moderator that was cited by several participants was that of work or employment. This was discussed in terms of both the impact that illness had on participants' ability to work (and the subsequent impact that this had on their illness), and the relationship between work and identity. Participants reported that having to reduce their employment commitment, or not being able to work at all, had been one of the most difficult impacts of their illness. This was discussed both in practical terms (financially, socially) as well as at a more abstract level such as impinging on their sense of being useful and productive in

society. The latter was often reported as being a key element in how participants defined themselves as individuals, and also in the way in which others saw them, and formed part of the wider issue of participants' sense of identity as a whole. Whilst some described work as a source of stress that triggered or exacerbated problems, it was more frequently cited as something that provided not only structure and activity, but also a more fundamental meaning to life and as contributing to a person's self-esteem:

*P7 – “It was just like somebody switching on a big sun – I just felt really good and it was just like ‘they’re doing this because they obviously value me and they want me to stay in the company.’ And that was the very first time that I saw myself as being good at my job.” (pg 8, line 352)*

The final aspect of this category related to *being well*. Participants described this not as a one-dimensional state but as a fluctuating sense of their own well-being, complete with indicators that they had come to recognize over an extended period of experiencing mental health problems - for example:

*P2 – “some spells are a bit better than others but I’ve never managed to get completely off medication, so I’ve never been completely well. It’s just a lifting of mood, a noticeable increase in enthusiasm which when I’m not well I have no enthusiasm for anything – no motivation, but when I have been well I’ve been more focussed on things.” (pg 1, line 23)*

Being well was also conceptualized as being different from a return to a previous state, and more to do with accepting (and enjoying) one's current mental health status:

*P3 – “I just feel that, here and now, I’m happy. What went before, if I think about it too much I get depressed. And before that again, was very happy – really happy. But I quite like where I am. I’m quite happy where I am. I just hope the future brings...if I don’t get better, I’ll be OK. ...And maybe I’ll never be what I was, but if I can cope the way I’m coping, I think I’m going to be OK. I’ll never be the outgoing person I was, and I’ll maybe always put more into something than’s necessary, but that’s not a problem as such. I’ve accepted that.” (pg 11, line 481)*

### **3.3.2 Treatment**

The second category of participant responses related to treatment. *Getting help* was a topic that some participants spoke about, both in terms of their attempts to access help and the impact that receiving help had. Participants spoke of trying to get professional help only once they had come to a decision in their own mind that they needed help and were ready to accept it. Participants also spoke of their relief and gratitude for the help they had received, whether this had come from professionals or in the wider sense of practical help from family and friends. Clear links were made between the way in which participants experienced receiving help and the attitude adopted by the professionals supplying it – especially in terms of respecting clients’ choices and collaborating with clients.

Most participants spoke to some extent about their experiences related to *medication* (which, as the results of the demographic questionnaire show, featured in the lives of all participants throughout their illnesses). For many, there was an acknowledgement that medication had been beneficial. However, there was evidence in some participants’ testimonies that the benefits had to be weighed against the disadvantages of medication:

*P5 – “I had a severe reaction to Prozac – I thought I was going completely off my head when I was into the first 3 or 4 days of that and I’ve been able to reduce my dosage now. I’ve been on...I started at 20mg a day, I’ve gone up to 40 but I think that’s actually interfering with my thinking, in that it’s taken the edge off.” (pg 8, line 387)*

There were also links between how medication had been used and issues related to power in the client / service provider relationship. Participants reported that medication was one area where they felt relatively powerless, especially at times when they had been unwell:

*P1 – “I was actually put onto Clomipramine I think it was, which I wasn’t that happy about, being pregnant, but it was a case of ‘you have to go on it and that’s it’, because you’re so low you must go on it...” (pg 5, line 216)*

*P7 – “So I went to the GP who’d put me back on the medication and that went on for a few months, where I was going back all the time saying ‘I’m not feeling any better’ and he’d just put my meds up.” (pg 1, line 47)*

On reflection, most reported that medication had helped them on their journey, although resentment at having to take medication and a desire to be medication-free were also sentiments that were expressed frequently. Many participants spoke of their desire to manage without medication but expressed concerns about the possible negative impacts on their continuing health:

*P8 – “Well, I think one thing that any psychiatric patient that you had in here would say is that I’d really like to not have to take drugs. That’s quite an important thing. Sometimes when I’ve been ill I’ve stopped, and of course I’ve ended up on the ward. But if I wanted anything out of the system it would be to come off drugs.” (pg 11, line 517)*

Participants also spoke about the way in which medication and the sense that they were 'well' were inextricably linked:

*P2 – “some spells are a bit better than others but I’ve never managed to get completely off medication, so I’ve never been completely well.” (pg 1, line 23)*

### **3.3.3 Relationships**

A third significant area that participants talked about in relation to their experiences of mental health problems was that of relationships. The role of *other people* was generally considered to have the potential to make a positive contribution to recovery but was tempered by fears and reservations about the perceptions of others, and by negative experiences in the past. When discussing their interactions and relationships with others, participants spoke of both positive and negative aspects of interpersonal contact. The more negative aspects included being let down, abandoned or hurt by others. The negative nature of personal contact was not only characterized by experiencing others negatively; this aspect also extended to participants describing being unpleasant or hurtful to others, and the subsequent feelings of guilt that this caused them. Participants spoke about the difficulties interpreting what others had said, and the effect this could have on them:

*P5 – “I’ll think “Someone shouldn’t have been rude to me” but it’s almost like to get out of this fighting with reality. We can spend a lot of time in ours heads – “They shouldn’t have said that”, and on and on, but the fact is, they did and it’s our reactions to them and sometimes you can see that within yourself you’re actually doing the same thing.” (pg 6, line 294)*

*P6 – “I am very self-aware, and I can analyse situations, and at some point I do get there. But now it’s easier just to pick up the phone to {CPN} and say “This situation happened, what do you think about it ? Have I misinterpreted it ?” and things like that. That’s good because it causes me less pain, or pain for less time.” (pg 5, line 234)*

They also spoke of a tendency to be different with different people, depending on who they were and what their connection to others was. This emphasis on being more selective and in control of relationships to others also extended to making active choices in relation to who to engage with and choosing who to listen to:

*P1 – “I had a few conversations with a group of people, but from that I’ve made a friend and we now meet weekly to discuss things, because we have a common link, and we have both been discussing how this has affected us, and how we are with people... even my friends don’t really know me, because they don’t know how things have affected me in some ways.” (pg 11, line 489)*

Reference was also made to the changing nature of friendships that survived mental health problems into stronger, closer and more enduring relationships.

Participants spoke of a desire to have contact with ‘normal’ people who were not patients, but also made reference to the value they placed in the bond they had experienced with others with mental health problems. These relationships were described as being “deep and intense”, and participants gave accounts of a new-found freedom to talk about issues that might otherwise be taboo (such as self-harm and suicide attempts). However, participants also expressed reservations about making friendships with others with mental health problems, due to the fear of losing friends through, for example, suicide.



The perceptions of others were also cited as playing an important role in how participants viewed themselves, or were able to maintain relationships. Participants spoke of an internal struggle to relate their view of themselves to how they believed others saw them, the worry caused by focusing on this and the effects it had on behaviour (such as avoiding certain locations for fear of being seen, and spoken about). However, some participants reported that, as their illness and recovery had progressed, they had come to be less concerned about how others saw them. This was generally described as a more recent phenomenon that had only been possible after many years of being worried and affected by the opinions of others. One participant summed this sentiment up succinctly:

*INT – “So is there a bit of that where you get to a stage, as time goes on, when you care less what people think ?”*

*P8 – “Yeah – ‘Sod ‘em’ is one of my things. I often think like that – it’s their problem, not mine. But people’s attitudes do annoy me sometimes – if they get me at the wrong time I’m quite likely to tell people to f\*\*\* off !” (pg7, line 318)*

Linked to this was the phenomenon of relationships within the *community*. Due to the siting of the study, participants lived in small, relatively rural communities. They spoke principally of the problems that this had caused, especially in relation to preserving a sense of anonymity when unwell. One participant who worked in education reported:

*P2 – “...I was in hospital in (town) to begin with and I would be there as a patient in the lounge, and in would come some of the parents from the school would be there with their kids, so they’d be visiting their auntie, or their brother or someone, and*

*they'd be "Oh look" you know ? "Look who's over there" sort of thing. That kind of culture. That was quite difficult, being a local in a local environment, in a place where you're known – but there's no way around that."*

*INT – "I guess that's part of being in a relatively small community, and being in a job where you're so visible in the community..."*

*P2 – "Yeah, in (nearby city) it wasn't so much of a problem, because I didn't know anybody there." (pg 6, line 295)*

Perhaps as a consequence of this, and the difficulties that participants associated with coming into contact with others in various settings, several participants spoke of making an active choice to become more of 'a loner'. They described a preference either for their own company, or that of a small group of family and friends, and of avoiding conversations that might turn to the subject of their mental health:

*INT – "So is there a connection between, as you say, being quite happy on your own, being a bit of a loner, is there a connection between that and worries about what people will say, or what people will ask you about ? Is that the reason ?"*

*P3 – "I would say so, yes. It keeps me away from having to answer questions. I like to be on my own."*

*INT – "So it's a way of coping with other people's attitudes ?"*

*P3 – "Aye. I get a bit...if I am sort of held up by somebody I just sort of say "Well, you'll have to excuse me, I'm just away for me walk". I don't want to converse with them at all." (pg 4, line 195)*

Intrinsically linked to the issues surrounding interpersonal and community relationships were phenomena such as *disclosure*, *stigma* and the tension that characterized choosing *independence versus isolation*. With reference to *disclosure*, participants spoke of the difficulties they had experienced in disclosing the nature of their difficulties. In the light of the comments made regarding who to speak to, disclosure was described as a difficult task:

*P7 – “I just kept it in, so it was really hard for me to speak to people at that point, because I felt like they were...if they asked me questions I thought they were trying to get to know stuff about me, and I didn’t want to tell them that. If I had to tell them what was really going on in my head they’d see me for what I was, they’d hate me.” (pg 5, line 204)*

Participants also made reference to the *stigma* that they felt is still attached to mental illness. As a result, some participants cited secrecy and withholding information, even from family and partners, as a feature of their earlier experiences of mental health problems. However, participants also spoke of the benefits they had found once they had been able to talk about their problems, and the role that this had played in their recovery:

*P1 – “it was just the fact that someone was going to sit there and listen to me and not judge me, and together work out ways of coping. I think that what’s had the most positive impact on my recovery, because of the people I’ve known all along.” (pg 10, line 435)*

This was not only true of contact with professionals; the reactions of people in the community were sometimes surprising to participants:

*P2 – “There were, in fact, very sympathetic, and concerned. So, there’s a lot of goodness in people.” (pg 7, line 343)*

Regarding the decisions involved in making decisions about who participants engaged with, and how they did this, some participants spoke of the relative advantages and disadvantages of these decisions. They spoke in terms of

independence, which was generally seen as a positive trait. Participants believed they become able to function more autonomously, initially out of necessity due to their reservations about the reactions of others, and that this had benefits. Against this participants spoke of having to weigh the risks of isolation and reduced social contact.

*P1 – “Yeah, you get to be quite selective because certain people can put you down, even though they don’t know who you are or what you’ve got. But you choose the people who you feel more comfortable with, which is good and bad really, cos I can shut people out. Quite easily. And just get on with it myself.” (pg 12, line 516)*

This further underlines the impact that mental illness had on participants’ relationships, how these changed for a variety of reasons, and how some participants at least had come to see benefits of being more independent.

*Relationships with professionals* were also raised by some participants, and again both positive and negative aspects were reported. Many of the issues described under this sub-category related to power. This was cited in relation to the use of medication, participants’ perceptions that they had been taken into hospital for the convenience of professionals but without having their own wishes considered, the attitudes of some staff members and the physical environment, where clients and members of staff are separated by glass and security-coded doors.

In addition, participants described the frustration of having to repeat their stories several times (to different professionals). They also spoke of their anger at not being listened to or having their views taken seriously:

*P1 – “Just thinking about that, I’m sure there was one time when some sort of health professional, a doctor or whoever...in fact, it was the psychiatrist – she was doubting that I even had it ! That was a bit of a blow, because even though she was being quite helpful but she did say “It is so rare I’ll be very surprised if you have got it” and I was thinking “Crikey, but I’m sure, I’m absolutely sure of it really”.” (pg 11, line 464)*

Some participants also spoke of professionals who abused their position by inappropriate behaviour (such as attempting to start personal relationships with clients) and who terminated contact abruptly, leaving vulnerable individuals feeling confused and abandoned by the people they had assumed they could trust. For some, changes in key staff involved in their care also had practical implications:

*INT – “What is it about those relationships that’s so important, do you think ?”*

*P8 – “Erm...well, it’s fear of the unknown. Are they going to change...I did change consultants once, and my new consultant decided to change all my medication – quickly – and it was disastrous. I ended up on the ward. And that was one of my worst times.” (pg 7, line 342)*

In terms of the more positive aspects of professional relationships, participants reflected that they perceived the most effective professionals to be those who were honest, listened to them and had respected service users’ views and choices. Professionals who were prepared to work collaboratively were highly valued:

*P3 – “I don’t like being told what to do, I like to be asked, so he knows now that it’s a case of “well, what do you think ? Will we...?” You know ?”*

*INT – “So it’s more collaborative ?”*

*P3 – “Exactly. I mean, he’s very honest, which is another thing I appreciate. I really do.” (pg 2, line 69)*

*P6 – “I said something to him one time and he looked at me and said “But you’re the expert !” That’s how he works.”*

*INT – “That obviously works well for you, but do you think that could be difficult or off-putting for some people ?”*

*P6 – “Well, each to their own. But I think that people should...I trust that everybody knows what’s right for themselves, and it’s not for me to impose my way onto other people.” (pg 10, line 462)*

Professionals who care and understand were also reported as being amongst the more positive aspects of experiencing mental illness. There was also a sense amongst participants that professionals who were prepared to maintain a sense of optimism, perhaps when participants weren’t able to do so themselves, were vital to the recovery process:

*P6 – “...they hold a vision for me, that I still have those skills there, no matter what I do with them that I still have that capacity to be well. They’ve held on to that for me, especially {psychiatrist}, she’s said “You’ve coped really well, you can do this.” (pg 9, line 407)*

Power dynamics were also referred to in a more positive sense, with many participants describing an important role for professionals not only in holding hope and optimism, but also providing a form of ‘antidote’ to negative experiences that participants had in earlier significant relationships. Although not actively pursued in interviews, there may be implications here for both the effect of early attachment relationships on subsequent relationships (amongst which those with mental health professionals are likely to be critical to

individuals receiving treatment), and the restorative effect that a positive relationship experience may have on service users.

### 3.3.4 *The Self*

Issues related to the self formed the final major category that participants spoke about. Participants spoke about the *attitudes* that they had found had been important during their illness and recovery, and reflected that they had developed many of the more helpful attitudes as a result of their increasing awareness of the origins, nature and impacts of their problems. This was particularly true with regard to getting a better sense of perspective on their situation and problems, which was cited as being the starting point for the recovery process:

*P5 – “There have been times when I’ve been lying in bed and I’ve just wanted someone to come along and put a bullet through my head – not maybe really, but it’s felt like that. Just to stop my head being so...but almost being able to separate yourself from your thoughts, and to start to look at them, and I think having the time off work has been good. It’s allowed me to do that.” (pg 11, line 501)*

Other important attitudes included acceptance of their situation, determination, stubbornness, faith, positivity and the value of having a purpose or focus in life. These are perhaps best summed up by the following comments:

*P3 – “I feel I’ve accepted that what’s been has been, and what’s coming’s coming. And, as I say, I’m quite happy with that. The positive outlook is, when I was so bad and now I’m not so bad, I never thought I’d ever be as I am now. I didn’t think that would ever happen. So that’s been wonderful really.” (pg 12, line 580)*

*P2 – “You’ve just gotta keep going, have a purpose and try and keep going.” (pg 7, line 346)*

*Identity* was an area touched on by many participants. Some spoke of how this had become very closely linked with diagnosis, or how they had become to see themselves as part of a different sector of society – namely, those with mental health problems.

Consistent with the themes raised within the moderators and impacts sub-categories within the broader nature of problems category, work was cited as playing a significant role in how participants saw themselves. In addition, participants spoke of the sense of lost identity that resulted from having to give up employment:

*P2 – “I’ve learned that when you’re working, when you’re employed, then you’ve very much got a sense of identity. When that’s taken away from you, a part of your identity goes..... People say “What do you do ?” you know ? Are you a teacher, a doctor, a policeman or whatever. It’s always “what do you do ?” not “Who are you ? What kind of a person are you ?” It’s a label kind of thing, and if you lose that label you feel the loss of it terribly.” (pg 7, line 333)*

The idea of *being inauthentic* or ‘wearing a mask’ at some stage was another factor related to identity reported by participants. This was often mentioned in reference to past behaviour, in terms of putting on a face to please others, to be liked or accepted, or to hide the distress that participants were experiencing. For many participants, recovery had been accompanied by a determination to reverse this and to become more authentic, although this was often described as having its own difficulties:



*P5 – “So in a way I’m working on dropping this...self-created thing that I feel I need to be for others to like me. And so now it’s more “Stuff that !” – not to other people, but this false persona. I’m gonna be myself and see what happens. But it’s almost a kind of painful letting go, and I think maybe part of the crisis was realising that I can’t go on like this, and the worry about what would happen to me if I did lose this kind of security blanket, or thing that I felt would help me cope.” (pg 9, line 416)*

Becoming (or attempting to become) more authentic was connected to the broader theme of *the changing self*. Participants spoke of personality changes, and of the process of adapting to and accepting these changes. Once again, the idea of not returning to a previous personality but of adopting a new one was prevalent:

*P7 – “I’m getting back to that kind of person, but I’m getting back to a person I never was before, because I was never open before, and I would just worry about things – and now I’m not that sort of person anymore. I’ll just say what’s on my mind.” (pg 6, 283)*

In general, participants talked about ultimately having become a better person as a result of their experiences:

*P8 – “it all blew up, my depression kicked in and I had a massive breakdown. So that was our turning point if you like – we would always have had depression to deal with, but we always look on that as when our lives changed. And sometimes I think I came out of it better than I was when I went in.” (pg 8, line 390)*

Several participants also spoke of a desire to help others benefit from their experiences, by finding some way of repaying the help and support that they had received:

*P7 – “I thought I’ve had so much out of this hospital that it was a way of giving something back. I thought that even if one thing I say is useful, then that feels to me like paying back for all the help I’ve had.” (pg 12, line 561)*

### **3.4 The Emerging Theory**

The two highest-order concepts that arose from the study were those of reflection on experiences and the gradual integration of the outcome of these reflections into a new sense of self. These two concepts appear to be linked, as the latter occurs as a product of the former. This did not, however, appear to be a linear process; rather, it was dynamic, with reflection producing a degree of integration, which in turn prompted further reflection and so on. Participants spoke about a number of aspects of the reflective and integrative process, with the common overarching factor being that of personal growth and movement in a forward direction in terms of personal development.

Of particular interest were the descriptions that participants offered in relation to relationships in their local community, and the ways in which these affected participants’ choices related to disclosure of details of their illness, a concept linked to the notion of stigma. Mental health professionals were also cited as playing a key role in either facilitating or hindering recovery, not so much by what they did but rather by how they did it. Participants also spoke of their shifting attitudes towards their illness, their sense of identity and an awareness of being inauthentic. For most, this led to a sense of themselves as having changed as a result of their experiences. This was couched in terms of becoming

a better person, and for some included a growing desire to be able to give something back to their community or society at a broader level.

These particular aspects of participants' accounts of their recoveries are considered to have theoretical significance, not only because of the frequency with which they were referred to but also because they form the foundations of the process of reflection and integration that characterises recovery.

### **3.5 Reflection and Integration**

This broad theme can usefully be separated into two constituent parts which, although dynamic in nature, appear to rely on the reflective element occurring first in order to provide insights that are subsequently integrated into an individual's sense of themselves.

#### *3.5.1 Reflection & self-evaluation*

Participants spoke of a process whereby they had, at some point in their experience, begun to look backwards over their lives. For many, this took the form of a self-analysis of their early life experiences, their initial awareness of mental health problems, and an interest in the potential causes or contributory factors involved in their illness. Although there were no specific initiators for this process of reflection, participants often related the beginnings of self-reflection to arriving at a point in their lives (and in the progression of their mental health problems) where they felt a need to know more about their condition. For some, this was prompted by contact with a health professional – perhaps a GP, or a more specific mental health service contact. It appears that something about this

contact, or the setting events that led to it, triggered a realisation that knowing more about their condition might be the first steps in coping with their difficulties. For most, this first step was not directly linked to a sense of recovery. It was described as having a more immediate and functional purpose – by increasing their awareness of the origins of their problems, patterns in their illness course and the impacts their problems were having, participants were better placed to cope and seek help.

Central to the process of reflection was the process of individuals ‘re-telling’ their story. In practice, this had often happened in the course of a GP or psychiatric out-patient appointment, or as part of an in-patient stay, where participants told their story to someone else. However, the ‘active ingredient’ appears to have been the intrapersonal effect this re-telling had. By verbalising their story, participants had been able to make better sense of it themselves and were subsequently able to see their experiences, and themselves, in a new light. As a development of the research process, and by way of illustration of this phenomenon, participants were asked specifically about their thoughts on the experience of participating in the research interview. Several respondents commented that they had found having the opportunity to tell their story beneficial, because it had given them the opportunity (perhaps, for some, the first such opportunity) to reflect on their lives as a whole.

Only over time did the process of reflection begin to suggest ideas that might have a more fundamental and long-term benefit. Participants reported that reflection had led to a process of self-evaluation, which in turn led them to reconsider and revise the values that they had held up to that point in their lives. Participants commented that, prior to this stage, they had worn a form of ‘mask’,

a public face and personality where their values were guided by what they believed (or feared) others would think of them. The gradual process of questioning long-held beliefs and values was, therefore, the initial step in the process of becoming a more authentic & honest individual, ultimately culminating in the formation of new identity.

Similarities exist between the process described by participants and the approach of Narrative Therapy, devised by Michael White and David Epston (e.g. White & Epston, 1990). The central tenet of narrative therapy is that an individual's identity is shaped by the narratives (stories, accounts, personal histories etc) that they have about themselves, and that problems can be overcome by reflecting on particular stories that relate to them and 're-authoring' them in a new and more beneficial way. Narrative Therapy as a distinct therapeutic intervention has attracted its critics, not least from those who assert that narrative therapists might bring their own views, biases and perceptions to the process and so potentially contribute to the client's 're-authoring'. However, in a broader sense other researchers have pointed to the utility of narratives in helping individuals to better understand and come to terms with their difficulties. Roe and Ayelet's (1999) study (again working with individuals coping with psychosis) investigated the use of narratives as a means of coping with mental illness. The authors suggest that individuals used a variety of coping styles, such as separating their illness from their 'healthy selves', changing the meaning of psychotic experiences and using the 'healthy' self to affect the course of their illness (p376). The stages described in Roe and Ayelet's study also suggest a dynamic process, in which participants were ultimately able to integrate their experiences of illness into a revised, coherent identity for themselves.

The process of reflection described here then can be seen as the precursor to (and arguably a prerequisite for) the next stage of the recovery process; that of integrating newly-acquired insights, beliefs and attitudes about illness and its effects into a new version of self-concept.

### *3.5.2 Integration*

This process of reflection and personal re-evaluation was cited as the catalyst for a fundamental shift in how participants came to see themselves. Through this process, and the changes that arose from it, individuals began to change. As the variety of thematic categories produced by this research shows, participants discovered a diverse array of aspects to their experiences of illness. These ranged from the more pragmatic effects of their illness and the treatment they had received to more abstract concepts such as the ways in which their relationships with others had been shaped by, and subsequently influenced, their difficulties. Many reported that they realised that aspects of their previous behaviour, such as acting in ways that they believed would please others, was having a detrimental effect on their mental health. As a consequence, participants described a growing desire to be more genuine with others. For some, this meant being more open about their mental health problems and the effects their difficulties had. By a process of further continual reflection, participants reported that they began to realise that they had become a different individual in subtle but significant ways. As such, they became aware that they were unable (and generally unwilling) to return to a state or identity that pre-dated their mental health problems. In essence, their attitudes changed to one of acceptance of what had happened to them. They began to integrate their experiences of being unwell into their sense of themselves as individuals as a whole, not just individuals who

were ill or unwell. Their confidence in sharing, or at least not hiding, their mental health difficulties also increased. One participant eloquently described this as “feeling comfortable in my own skin”.

The effects of employing a more integrative style of coping with mental illness, as opposed to adopting a ‘sealing over’ strategy, have been investigated previously, specifically in relation to psychosis (Drayton, Birchwood & Trower, 1998; Tait, Birchwood & Trower, 2003; Tait, Birchwood & Trower, 2004). Integrative styles were characterised by “acknowledgement of, and curiosity about, the significance of psychosis and by active attempts to cope in managing the illness”. By contrast, ‘sealing over’ styles were typified by “cognitive and behavioural avoidance of the diagnosis and experience of psychosis” and were generally adopted early in the course of illness, as a way of mitigating the trauma associated with diagnosis and treatment (Tait et al, 2003, p124). The authors suggest that a sealing style is linked to impoverished psychological resources, which in turn are conceptualised as resulting from poor early parental attachment relationships. Tait et al (2004) theorise that these experiences also adversely affect adult attachment relationships, making engagement with services more problematic for individuals with a sealing over style, subsequently predicting poorer outcomes for these clients. More integrative styles were linked to less severe depressive symptoms and fewer negative self-evaluations (Drayton et al, 1998).

The current study offers two interesting prospects Firstly, the ‘integration versus sealing over’ model of coping styles may apply to a broader range of mental health conditions than Drayton, Tait and colleagues investigated. From the accounts of participants in the current study (none of whom had a diagnosis of

psychosis or schizophrenia) it appears that being able to integrate their experiences of mental illness into a new sense of themselves was a critical element of their recovery. Psychologically, this can be framed in a number of ways. Within a cognitive-behavioural framework, a sealing style shares features of maladaptive coping such as avoidance whereas a more integrative style is similar to the more adaptive coping methods encouraged therapeutically via exposure and belief modification. Similarly, in Dialectical Behaviour Therapy and Acceptance and Commitment Therapy terms, the notion of acceptance of their current mental state by individuals is a key component of treatment. Within the model emerging from the current study, acceptance was cited as one outcome of the reflective process, and a critical element in the process of integration.

Secondly, the evidence from the current study suggests that coping style may change over time. Participants' accounts of their own reflective process suggest that participants initially adopted a coping style that could be described as being comparable to 'sealing over'. Participants spoke of attempts to deny or hide their problems, playing down the impacts that their illness had, or believing that they were powerless to affect their symptoms or illness course in any way. However, through the course of reflection and the gradual processing of the discoveries and insights made, coping appears to have subsequently shifted to a more integrative style which ultimately triggered and later came to characterise individuals' sense of recovery. This more reflective perception of illness, and especially an increased awareness of the moderators of it, resulting in an integrated view of the self was accompanied by a sense that participants could cope better.



Participants referred to a realisation that they were able to influence their illness course, and to ultimately see their problems in a new, less debilitating light. This is consistent with the model of contextual coping approaches presented in Moos & Holahan's (2003) study. Moos & Holahan describe contextual approaches to coping (as opposed to more personally stable stylistic or dispositional approaches) as "a dynamic process that fluctuates over time in response to changing demands and appraisals of the situation. According to this model, one cannot adequately predict how individuals will manage a specific stressful circumstance without considering the unique adaptive demands of the situation and the associated cognitive appraisals individuals employ in interpreting the personal meaning of those demands." (p1390). The authors conclude that individuals are "active agents who can shape the outcomes of stressful life circumstances as well as be shaped by them" (p1399). The experiences of reflection and integration described by participants certainly suggest that this was a realization arrived at by the individuals in this study. The recognition that they could assert some control over their illness, and how they lived their lives overall, was a fundamental part of participants' attitudes towards the possibility of recovery.

Within participants' accounts there was evidence of a change in style that accompanied illness progression. These findings can be tentatively interpreted as suggestive of a developmental model of coping, with a more denying / sealing style predating a more accepting / integrative style. This shift to a more integrative approach may be a function of increasing age or extended experience of mental illness, or a combination of the two. Scioli, McClelland, Weaver & Madden (2000) compared the use of integrative appraisal processes with cognitive-behavioural strategies in groups of young adults and older participants

coping with chronic illness. They report that the younger adults tended to enjoy better morale by employing cognitive-behavioural strategies, whilst the older participants gained more benefit by deriving integrative meaning from their experiences. These findings appear to be consistent with the accounts of the current study participants. In general, the individuals interviewed were middle-aged and had several years experience of mental health problems. Most reported that an ability to reflect on their experiences and to integrate the meaning of them had only come relatively recently.

What is clear from participants' accounts of their recovery is that they see themselves as fundamentally different from their 'old' selves. They do not conceptualise themselves as recovered or recovering because they are free of the symptoms or effects of their illness. Instead they see recovery as a journey, a process of continual re-appraisal of themselves and their situation in which they are very much a 'work in progress'. By allowing themselves to assimilate their illness into their view of themselves, accept the present for what it is and to look to the future with hope they have found a way of overcoming the burden of mental illness. This is a living exemplar of the notion of recovery presented in various policy documents, where recovery is not defined as being simply synonymous with an absence of symptoms.

For most participants, the process of reflection and integration did not happen in a linear fashion, nor did it happen in isolation. Participants spoke at length about the influence of other people, both professionals and those within their families and communities.

### *3.5.3 The Role of Relationships*

Three important aspects of interpersonal relationships emerged from the data. Individuals' interactions with the local community were a specific interest and one of the sensitising concepts of the research, and were a phenomenon that most participants made reference to. Participants also spoke about the impact that their illness had on their partners and spouses. Relationships with mental health professionals were also discussed, in both positive and negative terms. Examples of the comments that participants made have been provided elsewhere in this report; this section deals with the potential impact of these relationships on individuals' recovery.

Meeting and interacting with others is generally considered to be an adaptive behaviour and is seen as being potentially protective against relapse, particularly in depression (Calsyn & Winter, 2002). Encouraging clients to increase social interaction and enlist social support are often active components in treatment protocols such as cognitive behavioural therapy, and there is no shortage of evidence linking social networks to recovery and relapse (George, Blazer, Hughes & Fowler, 1989; Corrigan & Phelan, 2004). However, there is evidence from the present study which perhaps indicates that caution needs to be applied when discussing this with clients, and that their individual circumstances are taken into account. Whilst it is acknowledged that participants' beliefs about those in the community may have been adversely affected by their mental state at the time, from a phenomenological point of view community interactions were often experienced as negative. Also of note is that these views had not changed over time; participants who considered themselves relatively well and 'recovered' continued to report that social interactions in the local community

had an aversive quality. Other impacts of illness cited by participants, particularly in relation to employment, may also have an impact on service users' access to social networks. Muller, Nordt, Lauber & Rossler (2007) point to the economic and vocational aspects of social networks "as they enhance or hinder access to social participation" (p564).

Encouraging social interaction and the enlisting of social support may still be appropriate. However, the data presented here suggests that, for this population at least, this may need careful planning and consideration of clients' wishes. Acknowledgement should also be made of the potential limitations experienced by service users who are not engaged in employment. Individuals may not want to engage in large group or community activities, and may have reservations about others' reactions. At worst, the prospect of social conflict arises. This has been linked to the onset of depression and post-traumatic stress disorder (Huhman, 2004); therefore, negative experiences of social situations may exacerbate rather than mediate symptoms, and potentially derail the recovery process.

The size and nature of the communities in which this research was carried out may have particular implications for this aspect of treatment. From participants' accounts of the difficulties experienced, particularly in phases of their illness where they felt particularly vulnerable such as in-patient admissions and the period immediately after discharge, a therapeutic focus on social interaction may be counter-productive if not addressed carefully, collaboratively and with particular consideration of service users' attitudes towards social contact at specific stages in their recovery.

Participants were often keen to point out the impact that their illness had on their partners. They described the detrimental effect this had on their closest relationships, and commented on the impact that this additional sources of stress had on their potential recovery. Participants remarked on the perceived lack of awareness of the effect of such stressors within mental health services, and highlighted the lack of formal support for informal carers. Participants asserted that providing a relatively low level of support for spouses and partners would go a long way to helping service users, in addition to the direct benefits to carers. This is a theme that is also reflected in both the Framework for Mental Health Service in Scotland (1997) and Partnerships for Care (2003 (a)) documents, where carers are seen as an integral part of service design and delivery and should be included in the inclusive approach to mental health care advocated by these policy documents.

Gavois, Paulsson & Fridlund (2006) used a Grounded Theory approach to investigate the factors that might be of most benefit to families of those suffering severe mental illness. Their study revealed four factors that were perceived as most beneficial; being present, listening, sharing and empowering. The comments made by participants in the present study would suggest that these factors would help carers to feel better supported, and would therefore alleviate the daily stresses associated with living with a person with mental health problems.

Participants' own relationships with mental health professionals was also cited as an important factor in individuals' experiences of mental illness, and therefore was considered to have had a profound influence on their recovery. Literature on the effectiveness of a variety of therapeutic interventions has cited the

therapeutic relationship as one of the most powerful and enduring predictors of outcome (e.g. Howgego, 2003), with commentators reporting a therapeutic impact of between ten and 40% (Beutler, 2001; Barkham, 1996). Originally the therapist was seen as the vehicle for change, although more recent models have defined the relationship as more collaborative, with the client as an active participant in the process. Okiishi (2003) proposed that factors specific to individual therapists have a significant effect on client outcomes, with some therapists achieving a rate of improvement ten times above the average whilst others produced a much slower rate of change and potentially an increase in symptoms. Unsurprisingly, in the current study participants reported that professionals who had acted inappropriately had been particularly unhelpful and were considered to have set recovery back considerably. There were also more subtle ways in which professionals had affected recovery, however. Participants were able to recall specific quotes from professionals (examples of both extremely helpful, and less constructive, comments were given), often from several years previously. It was apparent that these comments had affected service users deeply. In particular participants had valued comments or behaviour which had indicated that someone (usually a mental health professional) was able to maintain a sense of hope and optimism for their recovery. Perhaps more significantly, this did not only affect the participant at the time but had provided an ongoing source of optimism for an extended period. There is, then, evidence that therapeutic factors are not only important during treatment or in the acute phase of illness. From the experiences reported here, they continue to have an effect over longer timescales, and across a wider range of professionals, than the psychotherapy research suggests.

In the emerging theory the processes of reflection and integration, especially when facilitated and supported by mental health professionals, ultimately led participants to a stage where they believed that they had changed fundamentally as a person. This was seen as a positive change, and perhaps one of the most encouraging indicators of a sense of recovery was the desire expressed by participants to 'give something back'.

#### *3.5.4 Personal development / growth*

Within the views on personal change and growth expressed by participants, factors such as becoming more genuine or 'authentic' individuals, and having been able to learn and benefit from their experiences were common. Pettie & Triolo (1999) describe the recovery process as "a deeply personal process that includes two key developmental tasks: the struggle for meaning and the reconstruction of a positive identity" (p255). Previous studies into individuals' reactions to traumatic events have produced a dichotomous set of findings, placing making sense of loss against finding benefit in the experience. Within the benefit-finding literature, theorists have held differing views about the nature of the benefits reported. The central question in this area surrounds whether reports of benefits found through loss or trauma are genuinely about benefits and personal transformation, or whether they are representations of ways of coping with events. Even those who hold the view that benefits can be found disagree about the function that this activity has. Some see 'benefits' such as learning about personal strengths and gaining fresh insights into life's meaning as potentially mitigating feelings of loss. In this way, they are conceptualised as being adaptive in terms of preserving the idea that life has purpose and meaning (Frankl, 1962; Janoff-Bulma, 1992). In a similar vein, Taylor (1983) and Taylor &

Armour (1996) assert that individuals perceive negative or traumatic events as “wake-up calls” as a way of minimising the threat to one’s sense of self that such events would otherwise represent. Thus, as well as being seen as the actual losses or traumas that they were, events are reappraised as opportunities for growth. However, yet another group of theorists argue that traumatic events “can create true developmental change by confronting people with new situations and issues” (Nolen-Hoeksema & Davis, in Snyder & Lopez, 2005, p601).

Whatever the theoretical standpoint taken about the process and utility of benefit-finding, the kinds of benefits that have been reported are consistent across a broad range of traumatic events. Three types of benefit have been reported, namely growth of character, a gain in sense of perspective and a strengthening of relationships (ibid, p602).

From the accounts of mental illness reported by the participants in the current study, some element of trauma and threat to one’s sense of self (at least the self that became ill or unwell) appear to be present in the experience of chronic mental illness. It is therefore plausible that the kind of benefits found in other traumatic experiences, and the resulting personal growth, could occur through the process of reflection and re-evaluation that characterise recovery as described by participants.

This concept of personal growth, linked to an increased awareness of the nature of their problems and a shift in attitude towards acceptance, culminated in participants being able to see themselves as a better person. They strongly believed that their experiences had provided them with a unique insight into



mental illness that most mental health professionals do not have, and this appeared to give rise to the desire to 'give something back'. Most participants who spoke about this had some ideas about how they could do this. They reported a variety of ideas, ranging from providing support to other sufferers that they had met on their journey to training as counsellors and joining the mental health service. Participants expressed a belief that, as a result of their experiences, they were better placed to be able to help others construct their own recovery narratives and could hold hope and optimism from a standpoint of one who considered themselves recovered or recovering. There are echoes here of the recommendations in Delivering for Mental Health (Scottish Executive, 2006 (a)) related to peer support workers. Individuals who consider themselves suitably recovered and are keen to have an input to services may therefore be ideal candidates for further training in such roles.

### **3.6 Corollaries to / Limitations of the current study**

Through the practice of reflection that is embedded in the Grounded Theory methodology, and as a product of sharing the research proposal and findings with other mental health professionals via various presentations, a variety of issues related to the current study were identified. This section describes these and, where applicable, provides further commentary on their significance or details of the actions taken to mitigate against them.

#### ***3.6.1 Researcher Characteristics***

Various contributors to the development of Grounded Theory have asserted claims that, strictly speaking, the researcher should be 'naïve' regarding the topic or subject area being studied. From a positivist standpoint especially, the researcher would ideally induce all of the research findings from the data alone; in practice, this becomes virtually impossible when the researcher is already interested or working in the domain in which the research is conducted. Professional training and practice and personal and professional interests are likely to have some impact on both the choice of research topic, and the way in which the researcher conceptualises it. In addition, the researcher is forced to undertake some form of preparatory reading, in order to form a basis on which initial research areas and interview question sets can be based.

The remedy for this dilemma is the inclusion of reflexivity within Grounded Theory, both as a concept and a series of practical tasks such as the maintenance of a reflective diary (through the writing of memos) throughout the research process (Charmaz, 1990). This process ensures that the research process, and the

interpretations that the researcher makes about what participants have said, are made transparent both to the researcher themselves and to readers of the completed research. In the current study, the reflective process enabled the researcher to become aware of his interests and motivations for conducting the research, and also to the potential biases that this may have introduced. Steps were therefore taken to negate this as far as possible; the researcher was mindful to allow categories and themes to emerge from the data as far as possible, whilst recognizing that the terminology used was likely to reflect the researcher's training and practice as a Clinical Psychologist. Whilst this linguistic use inevitably imparts a degree of researcher construction to the findings it is hoped that, by openly acknowledging this, readers are aware of the phenomenon and are able to take account of it.

### *3.6.2 Sample Size*

Whilst the sample of eight participants was not extensive, the practical constraints of finding sufficient volunteers who met the inclusion and exclusion criteria within the research timescale necessitated a relatively small sample. In addition, recent literature suggests that theoretical saturation is generally achieved relatively quickly; Nixon and Wild (2008) assert that it is "...regularly achieved within 10 focus groups or individual interviews".

The processes of constant comparative analysis and theoretical sampling indicated that an adequate number of participant views had been elicited to achieve theoretical sufficiency. The current sample size is also consistent with that of many published Grounded Theory articles. It should be noted that the aim of the study was to suggest an emerging theory that would be suitable for

further investigation, and possibly subsequent validation through quantitative methods, rather than to produce a fully developed theory.

### *3.6.3 Data gathering*

Within qualitative research there are several accepted ways of gathering data, many of which were considered when designing the current study.

Service user research has been carried out by service users themselves (e.g. Rose, 2001) and has been found to have advantages in terms of participants being more relaxed and responsive. Given the resource and time constraints, and potential issues regarding confidentiality, this method was not considered appropriate for the current study. Service user researchers would have required training in the research philosophy and methodology, and would have needed to be included in the ethics application. It was considered that having a Clinical Psychologist as researcher would foster an empathic environment, would help develop rapport and be sensitive to participants' feelings or any evident distress. In the event, all participants appeared comfortable, with some reported believing that the experience of being interviewed had been a positive and beneficial one.

Focus groups are also a common way to obtain data from a number of participants relatively quickly. Whilst it was acknowledged that this method could have been a valuable source of data, it was also considered that a group setting may have been off-putting for participants. Ultimately the decision not to use focus groups appears to have been justified by participant comments, and the themes that emerged regarding stigma and disclosure.

It was considered possible that inviting participants to volunteer to take part may have attracted those clients who were the most vocal, confident or who had particularly strong opinions about their experiences, thus biasing the responses obtained. It was hoped that by carrying out interviews on a one-to-one basis with the researcher, participants who might not otherwise have come forward would feel able to share their views in a relatively 'safe' and non-judgemental environment. In the event this did appear to be the case, and those who did participate offered considered and highly reflective accounts of their experiences. Although some criticisms of services were made, most participants spoke predominantly about their own personal experiences and issues, mistakes they had made and how they personally had adapted to living with and had ultimately been able to recover from mental health problems.

#### *3.6.4 Data validity and reliability*

Although validity and reliability concerns are less prevalent in qualitative research than in quantitative studies, there are measures within qualitative methodologies that seek to ensure that the findings reported do accurately reflect the context in which the research took place. Researcher reflexivity is the principal method employed in Grounded Theory, and the steps taken to facilitate this have been outlined both in the Methodology section and the 'Researcher Characteristics' subsection of this part of this report.

In addition to the process of researcher reflexivity, data gathered in qualitative studies is often validated by methods such as re-interviewing participants to check for consistency and clarity of initial understanding or inviting participants

to review, comment on and if appropriate challenge the content of interview transcripts and the codings applied.

These were rejected at the design stage of the current study, as it was considered important to maximise service user participation and ensure participant protection by limiting the number of contacts with the research process. On reflection it would appear that participants would have been more than willing to have further involvement. Increasing service user involvement in the data validation process is one way in which further research of this kind could be improved.

Reliability and representativeness issues relate to whether data gathered in one study could be replicated on other occasions. This is less of a concern for qualitative studies, which seek to describe and explain phenomena in a specific setting, usually amongst a relatively small participant population. Therefore, qualitative results are not assumed to automatically generalise to other situations or settings. The present study aimed to discover the particular characteristics of recovery in a discreet population – i.e. that of individuals living in a geographical and socio-economic setting different from that investigated by other recovery-based research. It is therefore hoped that the findings could be replicated in the same or a similar population, and can be used to suggest a theory that would generalise to other similar settings. Potential ways of checking this might include having other researchers carry out similar studies in the same setting. Alternatively, researchers may ask an individual who has some knowledge of, but is not directly involved in, the research to review the data and to code some or all of the interview transcripts. The output of this ‘independent’ coding exercise could then be checked against the original researcher’s conclusions.

However, as every individual will inevitably bring their own experiences, thoughts and constructions to the research the extent to which this would ensure absolute representativeness is open to question. It should also be noted that the current research does not claim to suggest a universal theory of what characterises recovery in the UK, or even Scotland.

#### *3.6.5 Service user involvement*

Given the broader context in which this research was located – i.e. that of increased service user involvement in all aspects of mental health services – on reflection, service users could have had a greater degree of involvement. Their views could have been sought in designing the semi-structured interview questions, in order to ensure that all potentially relevant areas or aspects of the recovery process were probed. Similarly, those service users who did participate could have been invited to review the transcript of their interviews to ensure that the written account represented an accurate version of what respondents were trying to communicate. This would have provided an opportunity for corrections or elaborations to be made, thus providing a richer account of the recovery process. The level of service user involvement in the research process itself could have extended to involving them in interviewing participants. There may have been benefits in this, in terms of a greater degree of understanding and empathy with participants, and this may have elicited more detailed accounts of recovery. However, in the current study concerns around confidentiality, time and resources devoted to training interviewers and the protection of both interviewers and participants (given the lack of anonymity in such a small community previously discussed) precluded this.

It may also have been beneficial to ask the participants to review a draft version of the final report, particularly the analysis. This would have created a more collaborative analysis, in keeping with the spirit of service user involvement. In addition to producing an analysis that service users had an opportunity to contribute to, this process would have provided an added element of validation to the analysis itself.

Similarly, service users could have been more actively involved in the dissemination of the research findings. Ideally the results would have been presented to service user groups, although at the time of writing these do not currently exist in the study location. In addition, service users could be involved in the continuing dissemination of the results, therefore providing them with greater 'ownership' of the findings as well as more opportunities to influence the way that they are operationalised in service implementation and design. In effect, this would help facilitate the desire to "give something back" that some participants made reference to.

It is considered that these modifications may have both further empowered service users to influence the direction taken by the research, and improved the overall quality of it. Time and resource constraints were significant barriers to incorporating many of these modifications. The opportunity to redress some of these shortcomings, particularly regarding dissemination and further discussion of the findings, does however still exist and will be considered.



### *3.6.6 Study location*

It is acknowledged that the present study was conducted in a rural / semi-rural setting and that the results may not therefore generalise to different geographical or socio-economic settings. However, gathering data from such a setting was one of the key aims of this project, in order to identify factors that might make recovering from a serious mental health problem in such a setting distinct from more urban locations. The results of the data analysis indicate that the closeness of the local community in particular may differentiate service users' experiences of recovery from those living in large cities or conurbations.

## **4 Conclusion**

### **4.1 Summary**

The emerging theory then is one of a dynamic process of recovery, which takes place over an extended period of time. It is characterised by increased awareness of the nature, origins and impacts of mental health problems, achieved through a process of reflection and self-evaluation. Through this process and the integration of the individual's various experiences, individuals begin to develop a new identity and a renewed sense of meaning to their lives. This is often very different from that of both their pre-morbid state and the person that they were before the recovery process began. Recovery can therefore be seen as a process of personal growth. The acknowledged importance of relationships, particularly with others in small, close-knit communities, is an aspect of recovery that may be particularly pertinent in more rural or isolated settings. Relationships with those providing professional support is reframed in terms of therapeutic alliance. This concept, traditionally thought of as a key component in specific therapeutic interventions, appears to have wider ramifications and features strongly in service users' descriptions of their recovery.

Parallels with previous recovery research can be drawn. The importance of narratives has been highlighted in much of the existing recovery literature (e.g. Jacobson, 2001; Brown & Kandirikirira, 2007) and appears to have been a critical element in promoting recovery of the participants in the current study. Comparisons can also be made to the central themes of previous research; aspects such as relationships with others, views about the self and reflection on the nature of mental health problems appear other work (Laithwaite & Gumley,

2007; Jacobson, 2001). Themes such as the dynamic process of growth and personal transformation have also been cited previously (e.g. Mancini et al, 2005). These similarities support the validity of the theory that emerges from the current study. Subtle but potentially important differences are however apparent. The impact of a small and close-knit community was one aspect of this study which has not previously featured as emphatically as it does here. The desire to 'give something back' is also an interesting revelation, which has practical as well as theoretical implications.

It would seem that, in their growth as individuals and their quest to find meaning in their lives, individuals who have experienced mental health problems are no different from those who have not. Perhaps, in the light of the evidence presented here, these reflective and truly authentic individuals are actually better placed to achieve these developmental tasks.

## **4.2 Clinical applications**

Perhaps the most obvious guiding principle to emerge from this research, and one which mental health services have made significant progress towards in recent years, is that of actively including service users in their care and treating their views, wishes and perceptions as valid. There is evidence that assisting in the process of reflection on and integration of experiences, and moving towards the construction of a new sense of self, may be one of the principle tasks of any professional working in mental health services. Davidson & Strauss (1992) suggested that "interventions which instil hope, foster positive yet realistic appraisals of self, encourage building on existing strengths, and assist in the

process of monitoring and managing symptoms and compensating for areas of dysfunction may help to stabilise and enhance a patient's sense of self" (p142).

One potential way that Clinical Psychologists in particular can contribute to this process may be through the medium of psychological formulation. The process of gathering information to arrive at an initial formulation, and sharing that formulation with clients, has the potential to assist clients in constructing the narrative that this research has indicated is so important to helping service users cope with and ultimately recover from their difficulties. This research also suggests that service users may be better placed to construct their own narratives only after a number of episodes of illness or a protracted period mental ill health. As such, the assistance of a psychological formulation may be particularly beneficial to younger clients or those who have experienced relatively few episodes of illness, where it may serve to supplement service users' own reflective skills. In addition, and in keeping with the recommendations made in such documents as the British Psychological Society's "New Ways of Working for Applied Psychologists in Health and Social Care" (BPS, 2007), consultation by Clinical Psychologists to other mental health professionals could help to further the practice of applying formulation skills collaboratively with service users. In this way, service users may benefit from a structured approach to constructing a narrative around their illness.

Previous studies into psychosis (Tait et al, 2003, 2004) drew conclusions that recovery style was related to psychological vulnerability, which in turn was hypothesised as being influenced by attachment style. Although attachment issues were not directly investigated in the current study, this may be a) a fruitful area for further investigation in non-psychotic clinical populations and b) an

aspect of service users' early experiences that warrants investigation at assessment. It may be that early attachment experiences not only have a potentially predisposing effect regarding subsequent mental health problems, but may also give clues as to the coping style that those who do experience difficulties ultimately adopt. Furthermore, Drayton et al (1998) suggest that the origins of negative self-evaluations that feature strongly in depressive illnesses lie in childhood relationships, and insecure attachments in particular. They therefore assert that "the patient's relationship with the therapist or key worker would be central to the person's self-concept" (p280). The principle of a mental health professional acting as an 'antidote' to the effects of earlier interpersonal relationships is inherent in some psychotherapeutic treatment models (e.g. the concept of 'limited reparenting' in Young's Schema Therapy, 2003). There is evidence in the current study that this may extend beyond specific diagnostic categories and the boundaries of the formal therapeutic relationship. All individuals who work with those experiencing mental health problems have an opportunity to help service users revise their view of others and their own self-image, and ultimately have a facilitative and positive effect on recovery.

### **4.3 Possible areas for further research**

In the process of carrying out the current research, a number of topics that warrant further investigation have emerged. These may help to further substantiate the emerging theory, or to make it more robust in its application. Particular topics identified include:

- Investigating mental health professionals' views regarding what they believe constitutes recovery, and what factors might help or hinder it. Subsequent analysis of the similarities and differences between professionals and service users' views may help to shed light on how services could be better designed and operated;
- A more specific investigation into the role of attachment in the development of coping and recovery styles (building on Drayton et al, 1998; Tait et al, 2002 / 2003) to investigate whether the concept of 'sealing' versus 'integrative' styles might be valid in wider range of mental health problems;
- A detailed analysis of carers' views of the recovery process, their role in it, and the impact it has on them;
- Applying a similar methodology to the one employed here to other client groups, such as older adults, adolescents and clients with learning disabilities, to determine whether there are there differences in their experiences and styles of recovery.

#### **4.4 Researcher reflections**

The initial idea for my major piece of doctoral research was prompted by the literature on recovery style, specifically in psychosis. However, potential problems with participant recruitment and an interest in the broader topic of recovery generally led to the development of a proposal to undertake the present study. The concept of integration may therefore have (unwittingly) been in my mind when carrying out the participant interviews, coding and subsequent data analysis. Nonetheless, it was gratifying to be able to draw potential parallels

between the two areas of research, and to have the opportunity to both reflect on the clinical application of this knowledge and to suggest areas for further investigation.

My thoughts and feelings on this area of research, and the methodology employed, have developed considerably in the process of conducting the study. Although it has prompted much confusion and numerous headaches, I believe I have benefited from learning a new research methodology. For this topic in particular I believe I have gained much richer data from adopting a qualitative approach. I also believe I have a much greater appreciation of the elements that characterise recovery and some of the factors that can hinder it. The idiosyncratic nature of the recovery process for each individual has underlined my belief in the unique identity of service users, and I hope that my own clinical practice will be both better informed and improved by having undertaken this research.

The process of gathering data by interviewing service users was something that I enjoyed enormously. It was a privilege to be invited to listen to participants' accounts of many years of difficulties, setbacks and yet ultimate personal growth and development in very challenging circumstances. The resilience and tenacity of participants to deal with difficult, often seemingly impossible situations, and to emerge feeling they had benefitted in some way, was humbling. I was also struck by the humility of the participants themselves. All were very honest, reflective, and many shared a desire to help others and, where possible, to prevent further suffering. In the process of interviewing service users I was also reminded of the main reason for my decision to train, and the most fulfilling aspect of my job, as a Clinical Psychologist. Client contact, and the potential to be

allowed to facilitate positive change in the life of another person, is a rare and immensely rewarding honour.

I have experienced several personal losses, and my own life has seen significant change, during this research process. These have been incredibly difficult experiences for me, and I have found myself relying on family, friends and colleagues much more than I would have liked. However, this has also been a journey of considerable growth for me and, while I would have preferred to have made the personal discoveries that I have in a much different way, I do feel that I have emerged as a better person. I can therefore, in a small way, empathise with the experiences that the participants described. I hope that I can incorporate these insights into my professional practice in such a way as to be a more effective clinician.



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## **Appendix 1: Participant Information Sheet**



## Participant Information Sheet



### **Experiences of recovery in mental illness**

I would like to invite you to take part in a research study. Before you decide whether or not to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Please ask me if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

#### Purpose of the study

I am a Trainee Clinical Psychologist employed by NHS Grampian at \_\_\_\_\_ and am currently studying for my Doctorate in Clinical Psychology at the University of Edinburgh. My training requires me to complete a piece of research (my Doctoral thesis) as part of my final qualification. This research will be completed in August 2008.

I am interested in finding out more about how people who have experienced periods of mental illness think about and describe their experiences.

You have been invited to take part because you currently have some form of contact with mental health services in Moray. It is anticipated that between five and ten other people will be asked to take part. It is up to you to decide whether to take part or not. This information sheet describes the study, and you will be given a copy to keep. If you decide to take part in the research, I will ask you to sign a Consent Form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

#### What will happen if you decide to take part

You will be interviewed about your experiences of mental health difficulties. Interviews will be carried out at a location that is most convenient for you, as far as possible. This may involve attending your local hospital / health centre, or the Department of Psychology

You will only be interviewed once, and the interview will last a maximum of 60 minutes. Only yourself and the researcher will be present at the interview, so nobody else will hear or have access to anything that you say. Interviews will be audio-taped, so that they can be transcribed and the content analysed. A coding system will be used to identify participants so that anonymity is preserved. The audio-tapes will be kept in a locked filing cabinet and will be destroyed once transcription has been completed.

You will also be asked to complete a short questionnaire in order to provide basic information regarding your age, gender, treatment, education, accommodation and employment. This information will be amalgamated to provide information about participants as a group, and will not identify you in any way.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information which is published will have your name and any other personal details removed so that you cannot be identified from it.

Taking part will have no effect on the treatment or support you currently receive. If you decide to withdraw before an interview is conducted, you will not have to take any further part in the research. If you decide to withdraw after you have been interviewed, the tape will be destroyed and the information you provided will not be used in the research.

#### Expenses and Payments

Reasonable expenses (e.g. if you have to travel to take part in the interview) will be reimbursed to people who claim benefits, on production of a valid receipt. No payment is offered for taking part in the research.

#### Possible advantages involved in taking part

There are not expected to be any direct advantages to you personally from taking part in the study. However it is hoped that, by finding out more about people's experiences of recovering from mental health difficulties, mental health services will be better informed and will be able to offer an improved service in the future.

#### Possible disadvantages and risks involved in taking part

It is possible that talking about your experiences of mental health problems might cause you some distress. You will be able to bring someone with you to the interview if you choose, as long as this person does not contribute to the interview. If you do become distressed during the interview, you will be given the option to pause or stop the interview. You may withdraw at any stage. You will always have the opportunity to talk about your experiences to your key worker as part of your ongoing contact with the mental health service.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the North of Scotland Research Ethics Committee.

#### Publication of results

The results of the study will be published in the form of a written thesis which will be submitted to the University of Edinburgh. A copy of the final report will be made available to anyone who takes part in the research on request from the researcher.

#### If there is a problem

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. I can be contacted at the Department of Counselling and Clinical Psychology on . If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

#### Further information and contact details

For further information about the topic of this study, or details of the study itself, please contact the researcher. Contact details are provided below.

Paul Bibby  
Department of Counselling and Clinical Psychology

Tel:

Email:

This research is being supervised by:

Dr Juliana Macleod  
Clinical & Counselling Psychology Service Manager  
Department of Counselling and Clinical Psychology

Tel:

Email:

## **Appendix 2: Consent form**





CONSENT FORM



Centre Number:

Study Number:

Patient Identification Number for this trial:

Title of Project: Experiences of recovery in mental illness

Name of Researcher: Paul Bibby

Please  
initial box

1. I confirm that I have read and understand the information sheet dated November 2007 (Version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that my interview with the researcher will be audio-recorded for the purposes of transcription only, and that all recordings will be securely stored and destroyed once transcription is complete.

4. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

5. I agree to take part in the above study.

.....

.....

.....

Name of Participant

Date

Signature

.....

.....

.....

Name of Person  
taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file.

### **Appendix 3: Participant advertisement**



**VOLUNTEERS NEEDED**



## **Are you recovering, or have recovered, from a mental illness ?**

I am a Trainee Clinical Psychologist based at the Department of Counselling & Clinical Psychology at . I am interested in finding out about how people who have experienced periods of mental illness think about and describe their experiences, as part of my doctoral thesis research project.

Anyone who is between 18 and 65 and considers themselves to be recovering or recovered from a mental illness can volunteer to take part in this research.

Volunteers who wish to take part will be interviewed about their experiences of mental illness. Interviews will be arranged at volunteer's convenience as far as possible. Each interview will take no more than 60 minutes, and each volunteer will only be interviewed once.

The study will be explained in full to volunteers once initial contact has been made. All volunteers will be free to withdraw from the research without giving a reason, and this would not affect the standard of care you receive. Confidentiality will be assured throughout the research process.

The findings of this research will be used to improve mental health professionals' understanding of how people experience mental illness. The intention is to try to improve the service provided to clients of mental health services in Moray.

If you are interested in volunteering please contact me, either by post, telephone or email (contact details are below).

Paul Bibby  
Department of Counselling & Clinical Psychology

Tel:  
Email:

#### **Appendix 4: Demographic Information Questionnaire**



## **Demographic information**

In order to be able to carry out some basic analysis on the demographic characteristics of all the people who take part in the research project, participants will be asked to provide information about themselves. This will not identify them in any way, and will only be used to provide general information about the population sample used in the research.

Please provide the following information (\* = delete as appropriate)

**Sex**                      Male / Female\*

**Age**                      .....

### **Diagnosis**

'Official' (if known) .....

Personal opinion / diagnosis .....

### **Treatment**

Have you taken medication in relation to your mental illness in the past ?

Yes / No\*

Do you take medication for your illness at present ?

Yes / No\*

Have you received treatment for your illness other than medication in the past ?

Yes / No\*

Are you receiving treatment for your illness other than medication at present ?

Yes / No\*

**Education** (please tick the highest level of qualification that you have attained)

No formal qualifications

'O' levels / Standard grades

'A' levels / Highers

Further education qualifications (SVQ, HND, HNC etc)

University Degree

Masters degree

Doctorate / PhD

Apprenticeship


**Living arrangements** – please tick the option that best describes your current situation

Live alone without support	<input type="checkbox"/>
Live alone with support	<input type="checkbox"/>
Live with family	<input type="checkbox"/>
Live with partner / spouse	<input type="checkbox"/>
Live in supported accommodation	<input type="checkbox"/>

**Employment** – please tick the option that best describes your employment situation

Employed - full time	<input type="checkbox"/>
Employed - part time	<input type="checkbox"/>
Self-employed - full time	<input type="checkbox"/>
Self-employed - part time	<input type="checkbox"/>
Voluntary unpaid - full time	<input type="checkbox"/>
Voluntary unpaid - part time	<input type="checkbox"/>
Supported employment	<input type="checkbox"/>
Homemaker / Housewife	<input type="checkbox"/>
Retired	<input type="checkbox"/>
In education	<input type="checkbox"/>
Claiming benefits	<input type="checkbox"/>

Please return the completed questionnaire to the researcher.

Thank you for completing this questionnaire.

## **Appendix 5: Semi-structured interview schedule Version 1**



## **Semi-structured interview schedule**

Main questions / areas to explore (questions in brackets are possible follow-up questions):

1. Can you tell me a little about your illness ?
2. Were there negative elements of your experience of mental illness ?  
(What were they ?)
3. What was the hardest part ?
4. Were there things that helped you, or made the experience easier ?  
(What were these things ? How did they help ?)
5. Were there any positive elements in your experience of mental illness ?  
(What were they ?)
6. Have you learned anything from your experiences ?  
(What have you learned ? Can you describe what you have learned ?  
Have you been able to use this in your life ? How ?)
7. Do you feel that your experiences have changed you in any way ?  
(How do you think you have changed ?)

### **Themes to explore:**

- Recovery
- Mental illness as a 'journey'
- Positive and negative experiences
- 'Meaning' in mental illness



**Appendix 6: Ethics Committee / NHS Grampian Research & Development  
Department correspondence**



**North of Scotland Research Ethics Committee (1)**

Telephone:  
Facsimile:

04 October 2007

Mr Paul Bibby  
Trainee Clinical Psychologist  
NHS Grampian  
Department of Counselling & Clinical Psychology,

Dear Mr Bibby

**Full title of study:** Experiences of recovery in mental illness  
**REC reference number:** 07/S0801/123

Thank you for your application for ethical review, which was received on 04 October 2007. I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 25 October 2007.

**Meeting arrangements**

**The meeting will be held in the Conference Room on 25 October 2007 at 16:00.**

Applicants are invited to attend the meeting in person as this may avoid the need to request further information after the meeting, enabling the Committee to make an application decision more quickly. However, it must be emphasised that the Committee may or may not have any questions, which require personal input. In addition we do not know how long each application will be discussed for, making the accurate allocation of time slots for each individual researcher impossible. In response to these difficulties and to avoid wasted journeys and time for applicants we would recommend being available by telephone at the time of review, in order to answer any potential questions raised by the Committee.

Please let us know if you still wish to attend the meeting or would prefer to be available by telephone at the time of the review.

### Documents received

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.4	27 September 2007
Investigator CV	1	28 September 2007
Protocol	2	16 July 2007
Covering Letter		28 September 2007
Peer Review		11 September 2007
Interview Schedules/Topic Guides	1	01 August 2007
Advertisement	1.0	01 August 2007
Participant Information Sheet	2.0	01 August 2007
Participant Consent Form	1.0	02 July 2007
Clinical Trial Liability Insurance		20 July 2007
Liability and Professional Indemnity Insurances		20 July 2007
Demographic Information	1.0	01 August 2007

No changes may be made to the application before the meeting. If you envisage that changes might be required, we would advise you to withdraw the application and re-submit it.

### Notification of the Committee's decision

You will receive written notification of the outcome of the review within 10 working days of the meeting. The Committee will issue a final ethical opinion on the application within a maximum of 60 days from 04 October 2007, excluding any time taken by you to respond fully to one request for further information or clarification after the meeting.

### R&D approval

You should seek approval from the R&D office for the relevant care organisation to conduct this research at a NHS site. The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given.

Guidance on applying for R&D approval is available at <http://www.rdforum.nhs.uk/rdform>

### Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for NHS Grampian. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

07/S0801/123

Please quote this number on all correspondence

Yours sincerely



PP Miss Karen Gauld  
Ethics Administrator

**North of Scotland Research Ethics Committee (1)**

01 November 2007

Telephone:  
Facsimile:

Mr Paul Bibby  
Trainee Clinical Psychologist  
NHS Grampian  
Department of Counselling & Clinical Psychology

Dear Mr Bibby

**Full title of study:** Experiences of recovery in mental illness  
**REC reference number:** 07/S0801/123

The Research Ethics Committee reviewed the above application at the meeting held on 25 October 2007.

**Documents reviewed**

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.4	27 September 2007
Investigator CV	1	28 September 2007
Protocol	2	16 July 2007
Covering Letter		28 September 2007
Peer Review		11 September 2007
Interview Schedules/Topic Guides	1	01 August 2007
Advertisement	1.0	01 August 2007
Participant Information Sheet	2.0	01 August 2007
Participant Consent Form	1.0	02 July 2007
Clinical Trial Liability Insurance		20 July 2007
Liability and Professional Indemnity Insurances		20 July 2007



Demographic Information	1.0	01 August 2007
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### Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Acting Scientific Advisor.

It must be noted that full ethical approval for the study should not be assumed until you receive a final letter of approval.

### Further information or clarification required

- A14 - The committee suggests that for the researcher's safety a carer or relative should also be present during the interviews. Please comment.
- A11 - Please could you clarify exactly what the participants are being asked to do? The committee is unclear about the number of interviews each participant is being asked to do.
- A44 - Current MRC (Medical Research Council) Guidelines recommend that data be stored for 10 years for primary research data and 20 years for records relating to clinical or public health studies.

### Participant Information Sheet

- Please change 'Grampian Research Ethics Committee' to 'North of Scotland Research Ethics Committee'
- Please put the supervisor's details on the Participant Information Sheet.

### Demographic Information

- Please change 'Gender' to 'Sex'

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 29 February 2008.

### Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**07/S0801/123****Please quote this number on all correspondence**

Yours sincerely

*pp* *R. Johnstone*  
**Dr Alex Johnstone**  
**Vice Chair**

### North of Scotland Research Ethics Committee (1)

#### Attendance at Committee meeting on 25 October 2007

##### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr John Callender	Associate Medical Director	No	
Ms Jane Drury	Health Visitor	Yes	
Dr Helen Galley	Senior Lecturer in Anaesthesia & Intensive Care	Yes	
Dr Paul Haggarty	Senior Research Scientist	No	
Dr Morley Hutchinson	Lay Member - Retired Research Fellow	Yes	
Dr Alex Johnstone	Vice-Chair & Non-Medical Research Specialist	Yes	
Dr Julie Kelly	Scientific Advisor	No	
Mr Albert Mclean-Bullen	Lay Member - Farmer	Yes	
Mrs Kathryn McMullan	Pharmacist	Yes	
Mr Leslie E F Moffat	Consultant Urologist	Yes	
Rev Mark Rodgers	Lay Member - Hospital Chaplain / Minister	Yes	
Mrs Shirley Shay	Lay Member - Associate Solicitor	Yes	
Mrs Mary Simpson	Research Nurse	No	
Dr Angus J Thompson	Chair & Consultant Radiologist	No	
Mr David Wood	Lay Member - Retired Marine Supervisor	No	
Prof George Youngson	Consultant Paediatric Surgeon	No	

##### Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Karen Gauld	Acting Administrator
Mrs Carol Irvine	Acting Co-ordinator
Dr Rachel Venables	Acting Scientific Advisor



Direct Line:  
24 Hour Answering Service

Dr R Venables  
North of Scotland Research Ethics Committee 1  
Grampian NHS Board

15 November 2007

Dear Dr Venables

**NRES Application – reference number 07/S0801/123**

I am writing in response to the request for clarification I received following the review of my application at the review meeting on 25<sup>th</sup> October 2007.

**Further information / clarification requested**

**A14** – With regard to researcher safety, interviews will be carried out at NHS premises during normal office hours, where other members of staff will be present and will be made aware of the nature of the interviews taking place. They will therefore be available to assist or raise the alarm should the need arise. This situation reflects normal practice for Clinical Psychologists working with adult clients. The inclusion criteria for the research require that participants have at least one ongoing contact arrangement with a member of mental health services, ensuring that an element of 'risk assessment' is contained within the research protocol.

In addition, it is possible that participants may not feel comfortable discussing either their experiences or their views of the service and support they have received in front of a carer or relative. Insisting that they are accompanied may inhibit participants' honesty, which would in turn reduce the richness of the research. Participants will be offered the option of having a carer or relative accompany them, but this would be their choice and based on the principle that anyone accompanying a participant does not contribute to the interview.

**A11** - Each participant will be interviewed once only. Interviews will last for a maximum of 60 minutes, and will be audio-taped for later transcription. Should a participant experience any distress during the interview they will be given

extra time at the end of the interview to recover. The Chief Investigator will ensure that any support that may be required is organised, which may include contacting the participant's keyworker and/or GP. This would only be done with participant's permission, and/or at their request. Participants will be free to withdraw from the research at any stage without prejudice. In the event that a participant wishes to withdraw, the relevant audio recording would be destroyed without being transcribed and no information pertaining to that participant would be used in the research.

**A44** - The retention period for all data related to the research will be amended to 10 years. Data will be stored in a locked filing cabinet at the principle research site, as described in the original application.

Although no participants will be identified on audio recordings of interviews, it may be possible to identify participants by their voice. It is therefore proposed that audio tapes would be destroyed once transcription has been completed to protect participants' anonymity. Typed transcripts of all interviews would be stored with all other data as above.

#### **Changes to supporting documents**

The changes that the Committee requested to the Participant Information Sheet and Demographic Information Questionnaire have been made, and are indicated by italicised, underlined text in the enclosed documents. Version numbers and dates have also been revised.

I hope that the information provided here, and the revised supporting documents, are sufficient to allow you to confirm the Committee's final decision. Please do not hesitate to contact me if you require further information. I look forward to hearing from you.

Yours sincerely,

Paul Bibby  
Trainee Clinical Psychologist

Encs:  
Participant Information Sheet (Version 3.0, dated November 2007)  
Demographic Information Questionnaire (Version 2.0, dated November 2007)



**North of Scotland Research Ethics Committee (1)**

Telephone:  
Facsimile:

21 November 2007

Mr Paul Bibby  
Trainee Clinical Psychologist  
NHS Grampian  
Department of Counselling & Clinical Psychology,

Dear Mr Bibby

**Full title of study:** Experiences of recovery in mental illness  
**REC reference number:** 07/S0801/123

Thank you for your letter of 21 November, responding to the Committee's request for further information on the above research and submitting revised documentation.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

**Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

The favourable opinion is given provided that you comply with the conditions set out. You are advised to study the conditions carefully, in particular:

**Condition 1: Annual Progress Report**

Under the National Research Ethics Service (NRES) regulations NHS Research Ethics Committees are required to monitor research with a favourable opinion. This is to take the form of an annual progress report which should be submitted to the North of Scotland Research Ethics Committee (NOSREC) 12 months after the date on which the favourable opinion was given. Annual reports should be submitted thereafter until the end of the study.



Points to note:

- The first annual progress report should give the commencement date for the study. This is normally assumed to be the date on which any of the procedures in the protocol are initiated. Should the study not commence within 12 months of approval a written explanation must be provided in the 1<sup>st</sup> annual progress report.
- Progress reports should be in the format prescribed on the NRES website ([www.nres.npsa.nhs.uk/applicants/index.htm](http://www.nres.npsa.nhs.uk/applicants/index.htm)).
- Progress reports must be signed by the Principal Investigator/Chief Investigator.
- Failure to submit a progress report could lead to a suspension of the favourable ethical opinion for the study.
- Please note the Annual Progress Report is a short 3 page form which is extremely easy to complete.

**Condition 2: Notification of Study Completion/Termination**

Under the National Research Ethics Service (NRES) regulations researchers are required to notify the Ethics Committee from which they obtained approval of the conclusion or early termination of a project and to submit a Completion/Termination of Study Report. Researchers should follow the instructions on the NRES website ([www.nres.npsa.nhs.uk/applicants/index.htm](http://www.nres.npsa.nhs.uk/applicants/index.htm))

Points to note:

- For most studies the end of a project will be the date of the last visit of the last participant or the completion of any follow-up monitoring and data collection described in the protocol.
- Final analysis of the data and report writing is normally considered to occur after formal declaration of the end of the project.
- A Final Report should be sent to the NOSREC within 12 months of the end of the project.
- The summary of the final report may be enclosed with the end of study declaration, or sent to the REC subsequently.
- There is no standard format for final reports. As a minimum we should receive details of the end date and information on whether the project achieved its objectives, the main findings and arrangements for publication or dissemination of research, including any feedback to participants.
- Please note the Completion/Termination of Study Report need only be a summary document and should, therefore, be easy to prepare.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.4	27 September 2007
Investigator CV	1	28 September 2007
Protocol	2	16 July 2007
Peer Review		11 September 2007
Interview Schedules/Topic Guides	1	01 August 2007
Advertisement	1.0	01 August 2007
Participant Information Sheet	3	
Participant Consent Form	1.0	02 July 2007
Demographic information	2	
Clinical Trial Liability Insurance		20 July 2007
Liability and Professional Indemnity Insurances		20 July 2007

### R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from  
<http://www.rdforum.nhs.uk/rdform.htm>.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nationalres.org.uk](mailto:referencegroup@nationalres.org.uk).

**07/S0801/123****Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp *R. Venables*  
**Dr Angus J Thompson**  
**Chair**

Department of Counselling &  
Clinical Psychology



Direct Line:  
24 Hour Answering Service

Katy Booth - Data Co-ordinator  
NHS Grampian  
R&D Office

29 November 2007

Dear Katy

**NRES Application – reference number 07/S0801/123**

Please find enclosed copies of all correspondence that has passed between myself and the North of Scotland Research Ethics Committee regarding my research application. Hopefully this provides enough information about the queries the REC raised, my response and their final decision regarding ethical approval.

Please do not hesitate to contact me if you require further information about my research.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Paul Bibby'.

Paul Bibby  
Trainee Clinical Psychologist



## Research and Development



Date 6/12/07  
Ethics 07/S0801/123  
R&D Ref: 2007MH008

Mr Paul Bibby  
Counselling & Clinical Psychology

Enquiries to     Katy Booth  
Extension  
Direct Line  
Email

Dear Mr Bibby,

**Project title: Experiences of recovery in mental illness**

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project has R & D Management Approval to proceed locally.

Please note that if there are any other researchers taking part in the project that are not named on the original Ethics application, please advise the Ethics Committee in writing and copy the letter to us so that we may amend our records and assess any additional costs.

Wishing you every success with your research

Yours sincerely

A handwritten signature in black ink, appearing to read 'K Booth', with a stylized flourish at the end.

**Katy Booth**  
Data Co-ordinator



## **Appendix 7: Researcher memos**

## **Memo: Independence vs isolation ?**

*Written April 2008 - during coding 1st interview.*

An interesting one this - have to see what develops and if this theme re-appears in other interviews. This participant implied that there are two sides to the experience of mental illness in relation to other people:

- 1 - the fact that it brings out an independent streak (framed by this person as a strength, a positive aspect) but
- 2 - implied that it could lead to becoming a loner (leading to possible isolation ? a more negative aspect ?).

Also connected to trust and how the participant believed other people might perceive her - and how that affected how she was with people generally.

Mental illness changes relationships ?

*Further note made 19 May - after coding 3rd interview.*

Topic of becoming more of "a loner" (same terminology used) appeared again, in the context of managing social contacts, level of intrusion from people in the community. Again, framed by this participant as a relatively positive thing, and something that they made distinct efforts to preserve.

Re: being a loner, not as sociable etc – what influences this ? How does this impact on what we (think we) know about the value of social support in mental illness ? Perhaps not such a black and white issue – client's choice of social support seems more important; letting them choose who to involve and when etc, and being respectful of their wishes (which is another theme in the coding...)

## **Memo: Disclosures**

*Written April 2008 - after coding 1st interview.*

Seems to depend on what's being disclosed, who to and in what circumstances: compare...

*"PPNT 1*

*Yeah, I kept very quiet, not really able to talk about it, apart from the person who was living with me at the time would know that I was the type of person that had to clean."*

*with...*

*"PPNT 1*

*I remember bottling everything up, then talking to the psychiatrist on the maternity ward, who said to me "You're going to have to start talking to these nurses, they know" and so*

*I did, I did start talking to them and they were really good. They were really quite understanding and so that had a big effect..."*

Perceived or predicted likelihood of being understood the deciding factor, or (as in this case) being encouraged or directed to talk ?

Other possible influences are shame / concerns about how others will react...

*"PPNT 1*

*...some people understood, some nurses that I worked with, and others just didn't. They thought I was trying to pull a fast one and not do my job."*

Also seems to affect what other people are prepared to disclose:

*"PPNT 2*

*I've discovered that a number of my friends, who I thought were OK, have had their own problems in the past, who were perhaps experiencing some level of problems, going to see a counsellor or on mild medication or something like that, who it came out of the woodwork as it were, and who felt they could admit to it."*

Therefore:

- Changes relationships
  - Affects whether people (choose to ?) become isolated / less sociable
  - Ultimately could affect recovery - in terms of whether & when people choose to disclose, and how much or little they feel they might benefit from being open with others.
- What does this say about social support - how & when it's accessed, what form it takes etc ?

## **Memo: Medication**

*Written April 2008, coding 2nd interview.*

*PPNT 2 - "I've had 3 courses of ECT – the last was in the last year, a year ago – some spells are a bit better than others but I've never managed to get completely off medication, so I've never been completely well."*

A definite link made here between "being on medication" and seeing oneself as "well" - an illustration of how people perceive medication ? I.e. you can only be truly "well" if you're medication-free ?

Would the same apply for other (non-MH) problems ? Would someone with, say, diabetes, blood pressure probs, a heart condition see things the same way ?

Raises questions:

1. What defines being "well" ?
2. Would it be the same for everyone ?

*Additions following further coding / raising terms to concepts)*

"Being well" doesn't seem to be just about medication - there are other factors as well, such as acceptance, having a positive attitude / optimism, getting some perspective on what "being well" means, changing as a person, being able to do 'normal' things

### **Memo: Benefits from participation ?**

*Written May 08, whilst coding 3rd interview.*

Following interview, it seems (from my observation) that clients may benefit from the interview itself – does it provide an opportunity to take a lifetime perspective of difficulties, see their own themes in what's helped and what hasn't ?

No experiences of distress (so far, after 3 ints) and response seems positive.

Should I ask about this specifically at end of interviews ?

### **Memo: Value of research in practice**

*Written May 08, whilst coding 3rd interview.*

I'm already noticing the value of this research – I can sense what participants have said coming into my practice with other patients, when we're discussing their progress, their experiences of illness.

I'm keen not to jump to conclusions and treat these insights as results or firm certainties, but already I can sense that doing research of this kind can (and should !) impact on professional practice at an individual level - one of the main reasons for doing this (as well as one of the hopes that the research would achieve).

More to do with the process of the research than the specifics of what insights etc I'm actually having...

### **Memo: Impact of professionals' words**

*Written May 08 - after coding interview 3.*

It's noticeable how every participant has referred to what various professionals (GPs, Psychiatrists, Psychologists etc) have said to them, often several years previously, and quoted them verbatim. This seems to apply equally to things that were perceived both negatively and positively.

Do we always recognise the power of what we say, and the impact it has perhaps not only at the time, but in days, months or years to come ? People do remember them, and carry

them around for a long time. How aware are we, as clinicians, of this in our interactions with clients on a daily basis ? We may be more aware in e.g. crisis situations, in breakthrough sessions or towards the end of client contact, where we're summing up / drawing together themes etc from treatment - but what about the comments we make that seem throw-away, but may remain in the mind of the client ?

To what extent are we responsible for this ?

### **Memo: Power dynamics**

*Written May 08 (after coding interview 3)*

There seem to be a few examples of what could be seen as 'power' being exerted by professionals - e.g.

- use of medication, possibly against clients' wishes but not being allowed / given opportunity to object;
- being taken into hospital for professional's convenience but not necessarily considering the wishes of the client;
- not being listened to / having views respected (at least in participants' perception);
- attitudes of some members of staff - belittling patients
- even physical environment - being separated by glass in reception / nurses station

Participants being 'persuaded' by professionals' viewpoint / opinion - perhaps sometimes without questioning it (?). Participants are already in a vulnerable position / state.

What happens to the client's wishes in these situations ? Are they really ignored or treated as less important, or were they considered and accounted for but just not mentioned or portrayed this way by clients ?

Does class / level of intellect / education play a role ? One participant raised this as a possibility, and it was discussed at prelim results presentation (in terms of did level of education influence participation, and therefore skew the results somewhat ?)

### **Memo: Respect for choices**

*Written May 08 (after coding interview 3)*

Different people seem to want different things from care – not so much about one size fits all, but listening to clients and respecting their wishes / choices ?

### **Memo: Stigma & the local community**

*Written May 08, after coding 3rd interview.*

There seems to be a link between the stigma, shame, awkwardness etc that participants have reported they feel continues to exist related to mental health problems and the type of community that most of the participants live in.

Small communities seem to have benefits (in that generally they are perceived and, in some cases directly experienced, as caring places) but also have considerable drawbacks. They are considered to be less anonymous as bigger towns and cities, where people can - if they wish - 'disappear' and not have to face people that they know and who know about their problems on a regular basis. Instead, small communities seem to be experienced as claustrophobic, and the expectation at least is that others will gossip or be aware of (or want to know) the details of a person's problems. Interestingly, this may not be realised in people's actual subsequent experience - participants have reported that, in general, people have been supportive and discreet.

### **Memo: Personal growth**

*Written Oct 08, following completion of coding and drafting concepts hierarchy.*

Awareness and understanding of illness (development, impacts, changing nature etc) through reflection over the years has provided some patients with the opportunity to reach a level of acceptance of their situation. From this personal growth can occur, as can the wish to "give something back".

May not be about being happier, but about clients being more self-aware and therefore able to manage better, control what happens and reduce impacts of illness, whilst appreciating what they have at present.

Can't be rushed ?

Can be facilitated by narrative-type work, professionals taking the time and encouraging clients to take a life-long perspective ?

### **Memo: Work**

*Written Oct'08 following all coding completed and drafting of concepts*

Work / employment seems to be implicated in several ways:

- 1- Often one very significant factor to be impacted as result of onset or worsening of symptoms - the first thing to suffer (Tree nodes - Nature of problems/Impacts/Impact on work);
- 2 - Can be a moderator (+ve and -ve) of symptoms (Tree nodes - Nature of problems/Illness moderators/Importance of work);
- 3 - Has wider impacts on family (partner having to continue working etc), financial situation (Tree nodes - Nature of problems/Illness moderators/Importance of work/Impact on others)

4 - Big factor in identity - (Tree nodes - The self/Identity/Identity through work) and resulting effect on confidence, sense of purpose, satisfaction etc

### **Memo: Attributes & attitudes**

*Written Oct 08, following completion of coding and drafting of concepts hierarchy.*

Purpose and determination seem valuable attitudes - do people develop these, or are they part of the people who recover better / at all ? Again, time seems to play a role in developing these attitudes and increasing own sense of self-determination, self-efficacy etc.

Professionals have a role in supporting this through collaboration, maintaining hope & optimism when client can't manage it themselves.

### **Memo: Impacts**

*Written Oct 08, following completion of coding and draft concepts hierarchy*

Range of impacts of MI, many of which interact with each other. Complex picture.

Most significant impacts seem to be:

- on families, partners etc - resilience required by partners to stick with it when things get difficult. Raises issue of support for partners, who (participants feel) do not get enough formal support or recognition for the role they provide in supporting patients and maintaining their well-being;
- on self-esteem and general view of self. Much guilt about how others were treated when participants were ill;
- on work (links with 'Work' memo);
- related to losses - of work (and therefore identity etc) but also of friends, relationships, and of hope of recovery.

## **Appendix 8: Revised semi-structured interview schedule**



## **Revised interview schedule - Topics to address**

### ***Area 1 – Relationships to others***

- *Independence vs isolation, becoming “a loner”*
- *Other people’s roles*
- *The community*
- *Links to stigma, shame, guilt*
- *Disclosure, secrecy, and what affects them*
  
- What role do other people play
  - What roles
  - Who are the people
  - What affects the importance of their role
- Are other people’s perceptions / attitudes important ?
  - Why
  - In what ways
    - Good ways
    - Negative ways
  - How does / did it affect you
- What role does the community play
  - Is it important
  - How / why
  - (link to stigma, shame, guilt etc)
- Living &/or being treated in a small community
  - Does it make a difference
  - In what ways
  - Examples from own experience
- Have you noticed any differences in how you’ve been / how you are with other people in the course of your illness
  - What’s been important
  - Have things changed from how they were before you were ill
  - Has the nature of relationships changed

### ***Area 2 – The self***

- *Knowledge & awareness*
- *Own attitudes, perception of (changing) self*
- *Identity*
  
- Awareness of / own theories about origins of your MH probs
  - Have you any examples
  - How do you think this / these factor(s) affected you
  - What helps / affects this (becoming aware)
  - Does it matter
  - Does it help
  - Is there a negative aspect
- Are your own attitudes important
  - In what way
  - Attitudes to what
  - Are there particular (personal) qualities that are important

- Are there aspects of yourself that you've discovered / have you noticed changes in yourself

### ***Area 3 – Impacts of MH probs***

- What impact have MH probs had
- What areas of life in particular
- Are there things that have made probs better or worse / easier or harder to cope with
  - What are they

### ***Area 4 – Professionals***

- *Professionals' roles*
- *Power issues*
- Role of professionals
  - What helps
  - What doesn't help
  - Examples of good / bad experiences
  - Factors / qualities that help

### ***Plus...***

- Meaning of experiences
  - (How) have you made sense of what's happened ?
- Participation in interview
  - Initial thoughts
  - Helped in any way

### **Appendix 9: Category relationships diagram**

